

**Quality of Life After Stroke and Aphasia:
Stroke Survivors' and Spouses' Perspectives**

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Abstract

A thesis was completed as part of the author's Doctorate in Clinical Psychology. Having previously worked in research teams investigating the impact of stroke and aphasia upon individuals and spending two years working therapeutically with people with low mood and post-stroke aphasia, a passion for aiding this client group to achieve a good quality of life was developed. Furthermore, completing this work highlighted the paucity of good quality research including this population, despite having learned from personal experience that it was feasible to do so, given that the appropriate adaptations and considerations were made to accommodate communication difficulties. Subsequently, a need for further research regarding quality of life post-stroke and aphasia was acknowledged. An initial review of the existing literature regarding quality of life post-stroke and aphasia was conducted, to determine what was already known, and what remained to be found. The studies identified for review were subjected to evaluation. The outcome of the review suggested that quality of life was a complex, multifaceted concept, impacted by a number of factors, but that it was not possible to determine for certain what factors were important in achieving a good quality of life, primarily due to the methodological limitations of the studies forming the evidence base. Chiefly, the data collection methods used were seemingly inappropriate for people with communication difficulties. Thus it was proposed that the more aphasia friendly, Q methodology approach was utilised to gather the views of people with post-stroke aphasia about what factors were important to achieve a good quality of life. Six aphasic stroke survivors and five spouses completed a Q sort task, in which they were required to rank a number of statements depicting different factors related to quality of life, in terms of personal importance. Spouses did this task from the perspective of the stroke survivor. Ultimately, two factors were identified: 'returning to the pre-stroke self' which represented the stroke survivors of working age, and 'life beyond stroke, what's important now?' which reflected the views of the older, retired participants. The two factors were considered in relation to Erikson's (1968) psychosocial stages of development model and in terms of stroke recovery models (Holbrook,

1982; Kirkevold, 2002). Significant, strong and positive pair-wise correlations between the Q sort outcomes of the stroke survivors' and their respective spouses' suggested that spouses could reliably report the stroke survivors' views regarding quality of life. The importance of the findings in relation to the work of a clinical psychologist was subsequently considered.

What and How do we Know About the Factors Affecting Quality of Life Post-stroke and Aphasia?

Abstract

Background: In the UK, about 150,000 people experience a stroke each year, and about a third experience aphasia as a result. Stroke primarily affects those aged >65 years, and as the current UK population is aging, more people are likely to be affected by stroke and consequently aphasia. Rehabilitation services need to provide adequate and evidence based support for this client group. Clinical psychologists form part of the core stroke rehabilitation teams, thus it is necessary to understand what contributes to a good quality of life to be able to provide effective and appropriate therapeutic interventions.

Aims: A review of the most recent literature regarding factors affecting quality of life post-stroke and aphasia was conducted to determine (a) what is already known, and (b) the quality of the studies forming the evidence base. The ten papers included in the review were identified through a search of health related electronic databases, via Ebsco and Web of Knowledge hosts. Articles were included if the focus was quality of life post-stroke and aphasia from a psychological perspective, and excluded if they specifically evaluated an intervention or a measure, or were a review paper.

Main Contribution: The main factors found to impact quality of life for this population were: rehabilitation, independence, family and friends, developing a new identity, making adaptations to accommodate stroke symptoms, having a positive outlook, aphasia (severity and type), emotional wellbeing, educating others about aphasia and managing other health conditions. With regards to the quality of the studies included, there were a number of limitations, mainly concerning the aphasia-inaccessible data collection methods used, which then raised concerns about the validity of the findings. The need for further research in this area, using a more aphasia friendly data collection method was identified, and Q methodology was proposed as a viable solution.

Conclusions: Quality of life post-stroke and aphasia is a complex and multifaceted concept. Understanding this phenomenon is paramount to providing effective rehabilitation services. Currently, due to the quality limitations of the studies forming the current evidence base, it is not possible to make firm conclusions regarding factors impacting quality of life post-stroke and aphasia. Thus, further research, using the aphasia friendly Q methodology approach was recommended.

Key words: Aphasia, Stroke, Quality of Life

Introduction

Stroke and Aphasia

In the UK, about 150,000 people experience a stroke each year; it is the main cause of disability, and the third largest cause of death. Stroke affects people of all ages, but primarily those aged >65 years (Stroke Association, n.d.). The UK population is aging; there is an increase in the number and proportion of older people, accounting for 15% of the population in 1985, and predicted to account for 23% in 2035 (Office for National Statistics, 2012).

As the population ages, stroke is likely to affect a greater number of people, and rehabilitation services need to provide the most appropriate, evidence-based support, including clinical psychologists as part of the core stroke multidisciplinary team (MDT) (National Institute for Health and Care Excellence [NICE], 2013). Stroke results from an interruption to the blood and oxygen supply to the brain, which can leave stroke survivors with a range of physical, psychological and cognitive difficulties of varying severities (Willacy, 2012). Between 21-38% of stroke survivors experience aphasia, a form of communication disorder (Berthier, 2005). Six types of aphasia exist. Broca's (expressive) aphasia is associated with difficulties in articulating language, with relatively unimpaired comprehension. Wernicke's (receptive) aphasia is characterised by fluent but nonsensical speech and poor comprehension. Conduction aphasia is associated with an inability to repeat information, with other communication areas relatively unaffected. Transcortical Sensory aphasia is similar to Wernicke's aphasia, with echolalia; the uncontrollable repetition of words. Global aphasia is a combination of Broca's and Wernicke's aphasia,

resulting in poor comprehension and speech output, and Anomia is defined by the presence of word finding difficulties. People with aphasia may also find that their reading and writing abilities are affected (Lincoln, Kneebone, Macniven and Morris, 2012). Aphasia can therefore present in different forms and severities, and affects a large proportion of stroke survivors.

Quality of Life

Quality of life is defined as one's 'perception of their position in life, within the context of their culture and value systems, in relation to goals, expectations, standards and concerns, and is influenced by physical health, psychological state, level of independence, social relationships, relationships to the environment and comprising spiritual, religious and personal beliefs' (Stenner, Cooper and Skevington, 2003, p. 2161). A number of psychological theories address the concept of quality of life. An acceptance and commitment therapy approach emphasises achieving a mindful, meaningful and values congruent means of life (Harris, 2009), the hierarchy of needs model (Maslow, 1970) suggests that humans strive to attain self actualisation having met their physiological, safety, attachment, esteem, cognitive and aesthetic needs. Rogers (1961) agrees that achieving self actualisation leads to quality of life, but is gained through experiencing unconditional positive regard, exempt from conditions of worth, and the development of a positive sense of self (Carlson, Martin, and Buskist, 1997). Lastly, according to Erikson's (1963) psychosocial stages of development model, at each life stage, people must successfully resolve a social dilemma to achieve a good quality of life (Carr, 2007; McLeod, 2008).

Post-Stroke Aphasia and Quality of Life Research

Hilari, Needle and Harrison (2012) conducted a systematic review of the literature in September 2010 and critiqued 11 studies that (a) concerned the health related quality of life (HRQL) for aphasic stroke survivors and (b) used validated quantitative measures or conventional qualitative data analysis methods. Factors limiting HRQL included the

presence and severity of aphasia, emotional distress and depression, poor body functioning, other health problems and demographically, being older and female may have an influence when decreased social network and aphasia severity are considered. Stroke severity was rarely accounted for in the literature, which could confound the findings. Factors enhancing HRQL included being proactive in communication recovery, partaking in activities and removing barriers associated with aphasia, by understanding the disorder, educating others and promoting awareness, including to services, and development/ availability of aphasia-friendly resources. Looking positively towards the future, having goals and developing an adapted identity incorporating the changes and a collective identity with other people with post-stroke aphasia were also pertinent. Further influencing factors were the stroke itself, mobility, independence and the home.

Social support was a complex factor. Social network was more important to women than men, and living alone leads to poorer HRQL for men only. Perceived social support, particularly informational and social companionship were associated with improved HRQL. Low satisfaction with social network could negatively impact life satisfaction (Astrom, Adolfsson, Asplund and Astrom, 1992; Astrom, Asplund and Astrom, 1992) and loneliness could precede depression onset (Hilari *et al.*, 2010). People with stroke often lose friends due to a loss of shared activities, decreased energy levels, physical disabilities, aphasia, others' unhelpful responses (avoidance of contact and mocking of difficulties), environmental barriers and changing social preferences. Aphasia creates difficulties in maintaining contact with friends (writing or telephoning), having two-way conversations and using humour. (Hilari *et al* 2012; Northcott and Hilari, 2011).

The concept of quality of life post-stroke and aphasia is multifaceted, with contributing factors not working in isolation to exert their impact. Hilari *et al.* (2012) concluded that further research was required into this area, due to design and quality limitations of the present studies, raising issues of the validity of the current findings. This notion is supported by other authors. It is recognised that there is an absence of

research including individuals with aphasia, despite a high number of stroke survivors experiencing this disability; studies either exclude people with aphasia, or do not state their inclusion. Studies that do include this population present inadequate descriptions of the level or type of aphasia, exhibit a sampling bias towards those with mild aphasia, gather information via proxy respondents or collect incomplete data (Grohn, Worrall, Simmons-Mackie and Brown, 2012; Hilary, 2011; Hilari *et al.*, 2012; Mumby and Whitworth, 2013; Sinanović, Mrkonjić and Zečić, 2012). It is unclear from the current evidence what factors affect quality of life post-stroke and aphasia, and therefore unclear what interventions should be prioritised within rehabilitation services. The long-term rehabilitation after stroke guidance was established by NICE in 2013, and states the inclusion of clinical psychologists in the core stroke rehabilitation MDT (NICE, 2013). It is essential that professionals are aware of all of the issues that affect the quality of life of people recovering from stroke, and provide appropriate psychological interventions. It was therefore deemed necessary to explore the most recent literature in this area, published since September 2010, when Hilari *et al.* (2012) last reviewed the evidence-base.

Method

A review of the most recent literature was completed to (a) identify factors impacting quality of life post-stroke and aphasia, and (b) evaluate the studies included. A systematic search strategy was used to identify appropriate articles for review, as described below.

Search Strategy

Ebsco and Web of Knowledge hosts were used to search the following electronic databases: The Allied and Complementary Medicine Database (AMED), Medline, PsycINFO, SPORTDiscus, AgeLine, Cumulative Index to Nursing and Allied Health Literature Plus (CINAHL), Academic Search Complete, the eBook Collection, the Web of Science, Current Contents Connect and the BIOSIS Citation Index. The search terms used were to be found in the abstract/ topic, and were:

"quality of life" or quality of life or "life* changes" or "life* satisfaction" or "well being" or wellbeing or "adjust*"
AND
stroke or cerebrovascular accident or CVA
AND
aphas* or dysphas*

Limiters were applied to ascertain the most relevant articles. Articles had to be: peer reviewed, published between September 2010 and December 2013 and written in English language. Duplicate articles were removed. Exclusion criteria were used to screen the remaining articles. If eligibility could not be determined based upon the title, abstracts were considered, and if further clarification was required, full texts were read. Articles were excluded if (a) the focus was not about aphasia, psychological change, or quality of life, (b) the aphasia was not stroke-induced, (c) they were a review paper or (d) they were an evaluation of an intervention or a measure. Articles evaluating quality of life measures were excluded as they primarily concerned the validity and reliability of the measures, rather than the outcomes of administering them.

Appendix A1 shows how the 593 articles found via Ebsco using the search terms, limiters and exclusion criteria were reduced to seven appropriate articles, and Appendix A2, shows how 345 papers found through Web of Knowledge were reduced to three. Altogether 10 journal articles were eligible and were included in the review.

Results

Study Details

Appendix B shows the data extraction table, summarising the title and authors, aims, samples, methods, findings, strengths and limitations and relevance of each study. The studies were viewed as a collective sample; the findings and critique have been discussed as if the ten studies were a whole entity.

Study Characteristics

Seven out of the ten studies were cross sectional (Armstrong, Hersh, Hayward, Fraser and Brown, 2012; Brown, Davidson, Worrall and Howe, 2013; Dalemans, de Witte, Wade and van den Heuvel, 2010; Grohn *et al.*, 2012; Niemi and Johansson, 2013; Sinanović *et al.*, 2012; Williamson, Richman and Coyle Redmond, 2011). Two were cohort studies (Hilari, 2011; Mumby and Whitworth, 2013) and both included participants without aphasia; one used a control group of people with stroke (Hilari, 2011), and the other included a carer, a Stroke Association volunteer and a council worker (Mumby and Whitworth, 2013). The last study was a case control study (Cruice, Worrall and Hickson, 2011), using a control group of people without experience of stroke or aphasia. Six of the studies used qualitative methodology (Armstrong *et al.*, 2012; Brown *et al.*, 2013; Dalemans *et al.*, 2010; Grohn *et al.*, 2012; Mumby and Whitworth, 2013; Niemi and Johansson, 2013), and gathered data via interview. Of these, four also used quantitative measures to assess aphasia severity and/ or wellbeing or living with aphasia (Brown *et al.*, 2013; Dalemans *et al.*, 2010; Grohn *et al.*, 2012; Mumby and Whitworth, 2013). Four studies used quantitative methodology (Cruice *et al.*, 2011; Hilari, 2011; Sinanović *et al.*, 2012; Williamson *et al.*, 2011), using questionnaires to gather data such as aphasia severity/type, quality of life, functional abilities, daily activities, social support and psychological wellbeing.

Themes Across the Literature

Akin to Hilari *et al.* (2012), the results of the review have been 'synthesised descriptively' as the present studies also varied greatly in their use of design, methods, measures and samples. Eleven broad themes, across the findings of the ten studies were identified and are discussed below.

Rehabilitation. Grohn *et al.* (2012) identified the importance of rehabilitation post-stroke and aphasia. Two key ideas arose: (a) that of actively participating in the rehabilitation process, agreed by Armstrong *et al.* (2012) who acknowledged that being pro-active and taking control of

recovery was valued, and (b) the importance of the relationship with the therapists guiding their rehabilitation; they provided invaluable information and motivation. There was a particular appreciation of speech and language therapy, and a desire for extended input. Armstrong *et al.* (2012) found that participants were satisfied with rehabilitation services, although 2/3 self-discharged having received limited input.

Independence. Cruice *et al.* (2011) concluded that older people with aphasia were less independent than peers who had not experienced stroke. Reduced independence may contribute to a lower quality of life, as suggested by both Armstrong *et al.* (2012) and Grohn *et al.* (2012).

Family and Friends. Family and friends seemed to be paramount in the recovery process and to achieving a good quality of life, and benefitted the aphasic stroke survivor in a number of ways, as shown below.

Support. Family and friends provide a variety of support, particularly emotional and practical, for example, by offering reassurance and helping to regain confidence (Grohn *et al.*, 2012). Brown *et al.* (2013) found that positive communication and laughing with friends enabled individuals to live successfully with aphasia. Friends had helped stroke survivors to “maintain a positive outlook” (p. 171) and to “feel happy and loved” (p. 171) and similarly to the findings of Grohn *et al.* (2012), friends were useful providers of emotional support. Family seemed to have a similar role, in addition to aiding maintenance of pre-stroke roles (Armstrong *et al.*, 2012).

Activities. Brown *et al.* (2013) highlighted the benefits of completing leisure activities with friends. Socialising was found to be important by Niemi and Johansson (2013), with stroke survivors finding it helpful when others offered support to participate in activities, and showed empathy. Unhelpful behaviours included a lack of effort from others to involve stroke survivors, or purposeful avoidance. Additionally, people continued to derive some enjoyment from group participation post-stroke, but took a more passive role in this situation.

Changes and Challenges. Brown *et al.* (2013) found that friendships changed, or were lost post-stroke and aphasia, for a number of

reasons: increased physical disability creating fewer opportunities to meet, a greater reliance upon others, being in fewer social environments and difficulties with conversation. Both Brown *et al.* (2013) and Dalemans *et al.* (2010) found that others' lacked an understanding of aphasia, which impacted upon friendships; people presumed that it was a 'mental disorder' or that people with aphasia were 'crazy.' Stroke survivors often desired more friendships, but greatly appreciated those who remained in contact (Brown *et al.*, 2013). Lastly, Dalemans *et al.* (2010) acknowledged three factors that reduced social participation: (a) personal factors (motivation, and communication/ physical difficulties), (b) social factors (care givers' and communication partners' abilities and support) and (c) environmental factors (noise levels and familiarity of surroundings).

New Friends. Making new friends, through attending stroke/ aphasia support groups, or whilst in hospital improved quality of life. Through this means, support, advice and encouragement, was both received and given. Other benefits included meeting others who understood the challenges faced, and with whom communication was easier (Brown *et al.*, 2013; Grohn *et al.*, 2012). Armstrong *et al.* (2012) found that community participation through groups and activities was valued by aphasic stroke survivors.

Activities. Engagement in meaningful activities, for example, work, leisure and therapy, (Grohn *et al.*, 2012) was a significant contributor to an improved quality of life, with the quality rather than quantity of activities being most valuable (Dalemans *et al.*, 2010; Mumby and Whitworth, 2013). Symptoms of stroke and aphasia, such as reduced communication and physical abilities, fatigue and lowered confidence acted as barriers to activity participation, (Grohn *et al.*, 2012) as well as the work, family and social lives of those affected (Armstrong *et al.*, 2012). Feeling like a burden was a barrier to participation, leading to isolation (Dalemans *et al.*, 2010), but the support of other people to reintegrate socially, and to complete more activities helped to overcome this (Mumby and Whitworth, 2013).

A reduced confidence in carrying out activities was also found by Niemi and Johansson (2013), stemming from an uncertainty about the

ability to conduct activities post-stroke. Stroke survivors managed this by exposing themselves to activities, to 'test out' abilities and monitor improvements, thus increasing confidence. They found that some participants completed more activities post-stroke. Two forms of activity were helpful, those which improved communication, and those that were separate from aphasia, giving them a break from stroke symptoms, thus enabling people to connect with their 'old self.' The authors acknowledged the benefit of adapting activities and developing routine, and that there were mixed feelings about wanting support from others to carry out activities.

Identity. Maintaining pre-stroke roles, including those within the family, and vocational and skill-based roles was important in managing life with aphasia. Maintaining or renegotiating roles seemed to be associated with the sense of self and identity, which may need to be re-considered post-stroke, incorporating the stroke symptoms and health issues (Armstrong *et al.*, 2012).

Adaptations. Niemi and Johansson (2013) found that individuals gradually adapted to their new abilities, accepted the residual stroke symptoms and adapted their approach to completing activities accordingly. Mumby and Whitworth (2013) however, acknowledged a sense of discordance between accepting symptoms and maintaining hope for further recovery. They did find that adjusting to impairments by developing new strategies, led to improved quality of life. Strategies may involve taking more time to do things, asking others to adapt their communication, using communication aids and gaining advice from others with aphasia (Grohn *et al.*, 2012).

Positive Outlook. Optimism, hope, determination, gratitude, and an acknowledgement of recovery and progress post-stroke contributed to an improved positive outlook and an improved quality of life (Grohn *et al.*, 2012).

Aphasia. The presence of, severity and type of aphasia have been considered in relation to quality of life. Compared to individuals who did not have aphasia post-stroke, those with aphasia were found to have an overall lower quality of life and carried out fewer activities of daily living,

such as social and leisure activities, work and travelling (Hilari, 2011). Sinanović *et al.* (2012) found that lower quality of life was associated with greater aphasia severity, and that people with mixed non-fluent aphasia appeared to have the lowest quality of life, followed by those with Broca's aphasia. Conversely, Williamson *et al.* (2011) found no relationship between aphasia severity and quality of life, or between age or time post stroke. Therefore there is mixed evidence regarding the impact of aphasia severity upon quality of life.

Emotional Wellbeing. Cruice *et al.* (2011) found that those with and without stroke and aphasia had similar levels of overall psychological wellbeing, although those with post-stroke aphasia experienced more low mood, greater dependence and more physical problems. Mumby and Whitworth (2013) described an emotional journey following stroke and aphasia, beginning with fear, frustration and loss, eventually shifting towards more positive feelings, and with the use of humour and determination, a greater sense of self acceptance and worth. Reflecting upon recovery, identifying positive aspects of current lives, looking positively towards the future and rationalising the stroke experience contributed to the success of emotional adjustment.

Educating Others. Education for stroke survivors and carers about aphasia seemed to ease the adjustment process, in addition to raising awareness and educating other people including services, about aphasia (Mumby and Whitworth, 2013).

Health Conditions. Aphasic stroke survivors are likely to experience a variety of symptoms in conjunction with communication difficulties, which could also influence quality of life. Recovery from other difficulties, such as physical health problems (Worrall *et al.*, 2011) and other health conditions, e.g. diabetes or heart disease, is a key priority, and has been found to be of greater importance than communication rehabilitation (Armstrong *et al.*, 2012).

Conclusion. The current review identified similar findings to the work of Hilari *et al.* (2012), but added further detail to a number of previously identified themes. Activity participation was important, but specifically those activities associated with work, leisure and therapy, and

the quality rather than quantity of activity seemed to impact quality of life. Barriers to participation, such as reduced communication and physical ability, fatigue, lowered confidence and feeling like a burden were highlighted, as were the means of overcoming barriers, for example, by having the support of others to participate in activities, practising activities and monitoring improvements. Maintaining and/ or renegotiating roles post-stroke, particularly those within the family, vocational and skill based roles, contributed to quality of life, and was associated with ones' identity. Aphasia has previously been found to influence quality of life. However, the current study adds to this, by recognising the conflicting evidence about its impact, thus highlighting the complexity of this factor. Further to the need of being actively involved in communication therapy, an appreciation of the patient-therapist relationship was acknowledged. The experience of difficult emotions, such as depression, upon quality of life was similarly identified, but additionally, a journey from such emotions to feelings of self acceptance and worth was described, involving processes such as reflecting upon recovery, thinking positively about one's current and future life, rationalising the stroke experience and having a sense of humour. Lastly, it was apparent that family and friends were paramount to achieving a good quality of life, by providing support, helping to maintain a positive outlook and identity, and encouraging activity participation. Making new friends with shared experiences, through attending stroke groups, was also important and was a means of gaining support and an understanding of the challenges faced, and communicating with others with ease. Difficulties with friendships were evident when others did not understand the concept of aphasia, and consequently avoided contact. Finally, the current review identified additional influences upon quality of life, not commented upon by Hilari *et al.* (2012); the significance of making adaptations to ones' approach to activity completion, developing new strategies to accommodate residual stroke symptoms and introducing routine and structure.

Altogether, Hilari *et al.* (2012) concluded that the studies forming the current evidence-base exhibited a range of design and quality weaknesses, thus impacting the validity of the findings. The present

review also critiqued the ten studies included, to determine if similar conclusions were reached. The evaluation is presented below.

Critical Appraisal

Each study was critically appraised, using a number of tools: the Critical Appraisal Skills Programme (CASP; CASP International Network, n.d.), The Pocket Guide to Critical Appraisal (Crombie, 1996) and guidance from Greenhalgh (1997, 1997) and Greenhalgh and Taylor (1997). Below, the strengths and limitations displayed across the ten studies have been summarised.

Aims and Justifications. Each study clearly stated that its aims were to identify the factors impacting quality of life post-stroke and aphasia, primarily due to the lack of current research in this area.

Recruitment Strategies. Participants were recruited from a variety of sources: hospitals, neurology departments, speech and language therapists, rehabilitation practitioners, the Aphasia Association and community stroke/aphasia support groups. Two studies described the purposive sampling strategy used (Dalemans *et al.*, 2010; Mumby and Whitworth, 2013), and one study described the challenges faced when recruiting from this population (Armstrong *et al.*, 2012).

Participant Samples. The total number of participants with aphasia across the studies was 202 (96 female and 106 male); the largest number recruited was 51 (Sinanović *et al.*, 2012) and the smallest was 3 (Armstrong *et al.*, 2012), altogether, relatively small. None of the quantitative studies reviewed (Cruice *et al.*, 2011; Hilari, 2011; Sinanović *et al.*, 2012; Williamson *et al.*, 2011), presented power calculations, thus it was not possible to ascertain the appropriate sample sizes required to ensure that tests had enough power to detect difference between the participant groups (Pallant, 2010).

Across the studies, the participants' ages ranged from 18 years to 91 years, encompassing the entirety of adulthood. Stroke predominantly occurs in people aged 65+, but can affect people of any age (Stroke Association, n.d.).

All studies commented on aphasia severity, which was primarily assessed using the Western Aphasia Battery Revised (WAB-R; Kertesz, 2007) and the Frenchay Aphasia Screening Test (FAST; Enderby, Wood, and Wade, 1997). A sampling bias towards the inclusion of people with mild to moderate aphasia was identified. Six studies excluded individuals with severe aphasia, either explicitly via exclusion criteria (Mumby and Whitworth, 2013), or by stipulating the ability to partake in an interview (Grohn *et al.*, 2012; Niemi and Johansson, 2013), or that communication ability reached a particular cut-off score when assessed (Cruice *et al.*, 2011; Hilari, 2011; Sinanović *et al.*, 2012). Four studies included people who were not deemed to be aphasic based on WAB-R scores (Brown *et al.*, 2013; Cruice *et al.*, 2011; Grohn *et al.*, 2012; Williamson *et al.*, 2011;). Two studies stated aphasia type (Armstrong *et al.*, 2012; Sinanović *et al.*, 2012), although one did not describe this for all participants (Armstrong *et al.*, 2012). Two studies broadly described aphasia type (i.e. expressive or receptive) (Hilari, 2011; Mumby and Whitworth, 2013), and two provided a description of the communication problems endured (Cruice *et al.*, 2011; Niemi and Johansson, 2013). Just two studies mentioned type of stroke, distinguishing between ischemic/ haemorrhagic (Hilari, 2011; Sinanović *et al.*, 2012) and only one provided stroke classification and severity details (Hilari, 2011).

Lastly, the studies were conducted in a number of countries: four in Australia (Armstrong *et al.*, 2012; Brown *et al.*, 2013; Cruice *et al.*, 2011; Grohn *et al.*, 2012), two in England (Hilari, 2011; Mumby and Whitworth, 2013), and one in Finland (Niemi and Johansson, 2013), the Netherlands (Dalemans *et al.*, 2010), Vienna (Williamson *et al.*, 2011) and Bosnia and Herzegovina (Sinanović *et al.*, 2012). Thus the participant sample demonstrates a range of cultural and life experiences, but raises issues of generalisability, particularly if there are differences in conceptualisations of aphasia, or provisions of healthcare and rehabilitation.

Data Collection and Analysis. An evaluation of the methods used for data collection and analysis were considered separately for the qualitative and quantitative studies reviewed.

Qualitative Studies. Data collection and analysis methods, rigour of findings and reflexivity were considered.

Semi-Structured Interviews. All six qualitative studies used interview techniques, thoroughly describing the procedure and providing topic guides and sample questions. Only two studies declared saturation of data (Dalemans *et al.*, 2010; Grohn *et al.*, 2012), without stating this, it is unknown whether or not important information is omitted.

The interview method has advantages. Individual views about subjective experiences, such as quality of life can be attained. Open questions give participants freedom to respond in their own manner, and follow up questions can access further information and clarify meaning, aiding the discovery of viewpoints not considered by the researcher. Interviews can be a source of rich, in-depth data, which can be further enhanced by using other data collection methods, such as video recordings that capture gestures and expressions, or written diaries (Barker, Pistrang, Elliott, 2002; Dalemans *et al.*, 2010). However, as people with aphasia experience problems in understanding and/ or expressing language, questions may be difficult to comprehend, or to verbally respond to, particularly when needing to provide detailed answers. This could contribute to the identified recruitment bias towards people with mild aphasia.

Data Analysis. Of the qualitative research evaluated, Armstrong *et al.* (2012) was the only study that did not provide a clear account of their data analysis. This information is vital to enable the reader to comprehend the derivation of themes, and to have confidence in the findings. All studies included quotes to support the resulting themes, however, the inclusion of more quotes would provide additional evidence confirming that the themes truly represent participants' views. Three studies indicated which participants provided the quotes (Armstrong *et al.*, 2012; Dalemans *et al.*, 2010; Mumby and Whitworth, 2013) which was not the case for the other studies (Brown *et al.*, 2013; Grohn *et al.*, 2012; Niemi and Johansson, 2013). Without this information, it is not possible to determine any bias in participant representation.

Rigour. Methods used to ensure rigour, and therefore faith in the reliability and validity of the findings, included: using multiple analysts (Dalemans *et al.*, 2010; Grohn *et al.*, 2012; Mumby and Whitworth, 2013), professional validation (Niemi and Johansson, 2013) and respondent validation (Armstrong *et al.*, 2012; Dalemans *et al.*, 2010). One study did not discuss rigour of data analysis (Brown *et al.*, 2013).

Reflexivity. It is necessary to consider how the researchers' influences may impact the results. Issues of reflexivity were considered in three studies, specifically, the impact of the interviewer knowing the participants prior to interview. Niemi and Johansson (2013) stated that the researcher's knowledge was put aside, but did not state how this was achieved, but acknowledged that the relationship between interviewer and interviewee aided the acquisition of open and detailed answers, due to increased trust. Armstrong *et al.* (2012) did not disclose the impact of the interviewer knowing the participants, but did consider influences of the researcher's vocational and family background, and language differences between interviewer-interviewee. Lastly, Mumby and Whitworth (2013) stated that the researchers' had prior knowledge of the participants, but that initial recruitment occurred prior to getting to know participants, to reduce any bias.

Quantitative Studies. Data collection and analysis methods and issues regarding confounding variables were considered.

Questionnaires. The four quantitative studies reviewed made use of questionnaires to collect data, which can be problematic; (a) with people with communication difficulties, as reading and understanding items may be difficult, in addition to providing verbal or written responses, and (b) when gathering opinions about a subjective concept such as quality of life.

Studies have used aphasia friendly measures, to reduce the impact of language barriers, for example, four of the ten studies reviewed (Hilari, 2011; Mumby and Whitworth, 2013; Sinanović *et al.*, 2012; Williamson *et al.*, 2011) used the Stroke and Aphasia Quality of Life 39 Scale (SAQOL-39; Hilari and Byng, 2001; Hilari, Byng, Lamping and Smith, 2003a), one study (Grohn *et al.*, 2012) used the Successfully Living with Aphasia Rating Scale (Brown, Worrall, Davidson and Howe, 2010a) and the

Assessment for Living with Aphasia (Kagan *et al.*, 2011) and one study (Cruice *et al.*, 2011) adapted the Ryff Psychological Wellbeing Scale (Thelander, Hoen and Worsley, 1994), making it more aphasia accessible. All of the six studies that used questionnaires described and referenced the measures, but only two (Cruice *et al.*, 2011; Williamson *et al.*, 2011) commented on validity and reliability.

Questionnaires are not deemed the most appropriate tool to gather information regarding quality of life, as it is a subjective concept, having a different meaning to each person, and questionnaires may not be sensitive enough to capture such unique views. Questionnaire items may have a different meaning to each individual, again, that might not be conveyed (Rosenberg, 1995). Questionnaires designed by researchers often reflect their own values and beliefs, which may be different to those of the assessed population, particularly if researchers do not share the experiences as the participants, in this case, of stroke and aphasia. Lastly, questionnaire items designed to assess the impact of illness on quality of life, primarily address areas of which the researcher has prior knowledge, e.g. from clinical experience or past research, and may not focus upon areas unique to the individual participants (Stenner, Cooper and Skevington, 2003).

Data Analysis. The four quantitative studies reviewed all used parametric tests, but only one briefly justified their use by describing the normal distribution of their data (Cruice *et al.*, 2011).

Reported Values. The level of detail in the figures reported to support the findings varied across the studies. These figures are valued to enhance the readers' confidence in the accuracy of the results. One study used Pearson's r correlation, and reported the correlation coefficients (r) and significance (p) values for all results (Williamson *et al.*, 2011). The results of the other studies were not so clear. One study used t -tests and ANOVAs, and the majority of findings were evidenced by t values or f values, but this was not the case for all statements (Hilari, 2011). The third quantitative study (Sinanović *et al.*, 2012) used ANOVAs and Spearman's Rho tests. For the outcomes of the ANOVAs, f values were not reported, but p values were. No figures were presented to defend the correlation

findings. The last study (Cruice *et al.*, 2011) used T-tests and a correlation, although it is not stated which type of correlation. R and p values were reported for the correlation, and t values were reported for the T-tests.

Confounding Variables. Contemplation of potential confounding variables across the studies was limited. This seemed important as quality of life post-stroke and aphasia is impacted by numerous variables, which in turn can impact each other. One study did not consider any confounding variables (Cruice *et al.*, 2011), and three briefly considered other influences (Hilari, 2011; Sinanović *et al.* 2012; Williamson *et al.*, 2011). Of particular interest, was stroke severity. Only one study, of the total ten reviewed, reported this (Hilari, 2011), but did not discuss this as a potential confounding variable. Greater stroke severity is indicative of an increased number and severity of symptoms endured. Sinanović *et al.* (2012) recognised that individuals experiencing more severe forms of aphasia were likely to experience more physical difficulties, which can impact quality of life. Cruice *et al.* (2011) used a control group of people who had not experienced stroke or aphasia, thus the stroke itself would be a confounding variable, as other stroke symptoms could be responsible for the findings, but this was not acknowledged. Understandably, not all factors can be considered in each study, as the concept of quality of life is complex and multi-faceted. This highlights the importance of continued research in this area, thus expanding the evidence base and current knowledge.

Findings. Eight of the ten studies presented their findings in a clear and concise manner. However, in one study it was not obvious how all of the conclusions had been reached (Williamson *et al.*, 2011) and another provided lengthy and interesting discussions about the findings, but the abundance of information was difficult to assimilate, which made it difficult to determine the key findings (Mumby and Whitworth, 2013). All studies apart from one (Sinanović *et al.*, 2012) identified a clinical use for their research, and five identified areas of further research (Brown *et al.*, 2013; Cruice *et al.*, 2011; Grohn *et al.*, 2012; Hilari, 2011; Mumby and

Whitworth, 2013). Both of these factors contribute to the usefulness of the research.

Aphasia Considerations. The skills, willingness and knowledge of the communication partner can impact the social participation of someone with aphasia (Dalemans *et al.*, 2010). When completing research with people with language difficulties, it is critical to adapt interactions to maximise communication, and to minimise distress or frustration caused by difficulties in conveying information, meaning or opinions effectively. Adaptations most frequently used by the ten reviewed studies were the setting of data collection and use of communication aids.

Setting. Three studies (Armstrong *et al.*, 2012; Brown *et al.*, 2013; Mumby and Whitworth, 2013) provided participants with the choice of study location, although home address or hospital were primarily chosen. Four studies did not provide the choice, but conducted data collection at the participants' place of residence (Cruice *et al.*, 2011; Dalemans *et al.*, 2010; Grohn *et al.*, 2012; Niemi and Johansson, 2013), and three studies did not mention study location (Hilari, 2011; Sinanović *et al.*, 2012; Williamson *et al.*, 2011). Niemi and Johansson (2013) summarise the benefits of conducting research in participants' own homes; the safe and supportive environment can help participants to feel relaxed. It is known that some stress/ anxiety can improve performance, but excessive anxiety can hinder (Yerkes and Dodson, 1908), thus feeling at ease may facilitate greater participation in the research. Being in a familiar setting may provide cues that aid the participants in completing interviews or questionnaires, and being in the home setting may add richness to the data collected, by adding context and an understanding of the participants' background.

Communication Aids. Only two of the ten studies did not mention adaptations made to support communication with the aphasic stroke survivors (Sinanović *et al.*, 2012; Williamson *et al.*, 2011). Adaptations used by the other eight studies included the use of aphasia friendly questionnaires, comprising large fonts, emboldened key words, pictures and limited information on each page. The researchers administering interviews or questionnaires were often speech and language therapists

(SALTs), or other professionals that received training to work with people with aphasia, or who followed instruction from the Supportive Communication for Adults with Aphasia guidance (Kagan, Black, Duchan, Simmons-Mackie and Square, 2001) for example. On occasion family members were present to support the person with aphasia, in addition to identifying helpful communication strategies prior to data collection. Communication was adapted in different ways, via the use of probes, repeating/ summarising/ simplifying information, personalising questions, use of gestures or other supportive materials (Armstrong *et al.*, 2012; Brown *et al.*, 2013; Cruice *et al.*, 2011; Dalemans *et al.*, 2010; Grohn *et al.*, 2012; Hilari, 2011; Mumby and Whitworth, 2013; Niemi and Johansson, 2013).

Ethical Considerations. Seven of the ten studies made reference to the ethical approval received from university or ethics committees (Armstrong *et al.*, 2012; Brown *et al.*, 2013; Cruice *et al.*, 2011; Grohn *et al.*, 2012; Mumby and Whitworth, 2013; Sinanović *et al.*, 2012; Williamson *et al.*, 2011). When completing research with this population, it is paramount to consider the extent of the language difficulties and consequently, the impact on gaining fully informed consent. Only three of the ten studies discussed ethical procedures in relation to communication difficulties (Dalemans *et al.*, 2010; Hilari, 2011; Niemi and Johansson, 2013).

As evidenced, the reviewed studies display a number of strengths and limitations. People with post-stroke aphasia are a hard to reach population and are frequently excluded from stroke research, thus all attempts to raise awareness and to include this population in studies, allowing their voice to be heard, should be valued. A key strength across the studies were the adaptations made to accommodate the communication difficulties, considering their approach to data collection and style of communication. The problems identified were predominantly constrained to the design and methodology of the research; the use of small and biased participant samples, and of data collection methods that may not be valid for this population. Possible means of remedying these problems are discussed below.

Discussion

A review of the research investigating factors affecting quality of life post-stroke and aphasia, produced since Hilari *et al.*'s (2012) systematic review, was conducted. Due to an ageing UK population, stroke is likely to affect a greater number of people, and rehabilitation services need to provide appropriate support. NICE (2013) recommends that psychologists are part of the stroke MDT, and therefore an understanding of the factors affecting quality of life for this population is paramount to effectively work therapeutically people with stroke and aphasia, particularly if communication problems create difficulties for clients to convey this information. People with aphasia are often excluded from research, and the studies that have investigated quality of life for this population display a number of design and methodological limitations. The need for further research was therefore clearly evident.

Ten papers met the inclusion criteria of the current review. The criteria used was different to that of Hilari *et al.* (2012), who only included papers if they reported on HRQL. It was deemed appropriate to expand this criteria to incorporate papers that referenced quality of life, or factors known to contribute to this; this concept is multi-faceted, known to be influenced by numerous variables. Themes across the findings of the ten studies were descriptively assimilated, followed by an evaluation of their combined strengths and limitations.

The main factors found to affect quality of life included the importance of rehabilitation; taking a proactive role in this and developing a good relationship with the therapist, being independent but having family and friends for support and companionship. However, a number of barriers and challenges in maintaining friendships were acknowledged. Engaging in meaningful activities, such as work and leisure activities or those aimed to improve communication abilities was valued, with quality of activity being more important than quantity. Maintaining pre-stroke roles, and readjusting identity to accommodate stroke symptoms, seemed to be important, in addition to making lifestyle adaptations and using different strategies based to accommodate new abilities, but also to maintain hope for further recovery, and to have a positive outlook on life. The presence,

severity and type of aphasia were linked to quality of life, although due to mixed results regarding this factor, it was difficult to determine the exact impact. A journey from negative feelings such as low mood, fear, frustration and loss through to self acceptance and worth was apparent, during stroke and aphasia recovery. Education about aphasia was an important factor, for stroke survivors and their carers, and for the wider population, including for services. Recovery from other health conditions or stroke symptoms, in addition to the aphasia, was significant in achieving a good quality of life, and could even be more significant than communication recovery. The current findings added further detail to those of Hilari et al. (2012), and identified an additional factor; that of making adaptations to ones' life and identity, thus accommodating the residual stroke symptoms.

Altogether, it seems that a number of key factors are frequently associated with a good quality of life post-stroke and aphasia, most predominantly: spending time with family and friends, completing and adapting activities, maintaining pre-stroke roles where possible, but accepting the more permanent stroke symptoms, and altering the sense of self to accommodate these. This is useful to acknowledge when working therapeutically with this population, to understand what areas are important to prioritise in the rehabilitation process.

In agreement with Hilari et al.'s conclusions, was the finding that the studies reviewed showed design and methodology limitations. Primary concerns were that of small and biased samples and the use of aphasia-unfriendly data collection methods, including interviews and questionnaires, and their validity for use with people with communication difficulties, for reasons discussed.

Quality of life post stroke and aphasia, appears to be a complex phenomenon, with a number of factors exerting an influence. However, it remains difficult to conclude with certainty what the factors are and their exact influence, due to concerns about the methodological limitations of the studies forming the evidence base. It is therefore necessary to use a more aphasia-friendly means of collecting this data, which enables the inclusion of a sample of participants with a greater range of aphasia

severities to partake. It is proposed that Q methodology (Stephenson, 1953) could be a solution. Q methodology has been used to assess factors affecting quality of life in healthy participants (Stenner, Cooper and Skevington, 2003) but has not yet been used to determine such outcomes with aphasic stroke survivors. This method requires individuals to rate a number of pre-determined statements, using a psychologically significant scale, in terms of personal importance (Watts and Stenner, 2012), and is therefore less reliant upon communication ability, as participants are not required to give verbal or written feedback, and appropriate aphasia-friendly modifications could be incorporated into the materials used.

In summary, this review of the literature has expanded Hilari *et al.*'s (2012), findings about factors impacting quality of life post-stroke and aphasia, but agrees with their concerns about the quality of existing research. Therefore, further research in this area is required, using a more aphasia friendly data collection method. A proposed approach is that of Q methodology, which is less reliant upon communication ability than more conventional data collection methods.

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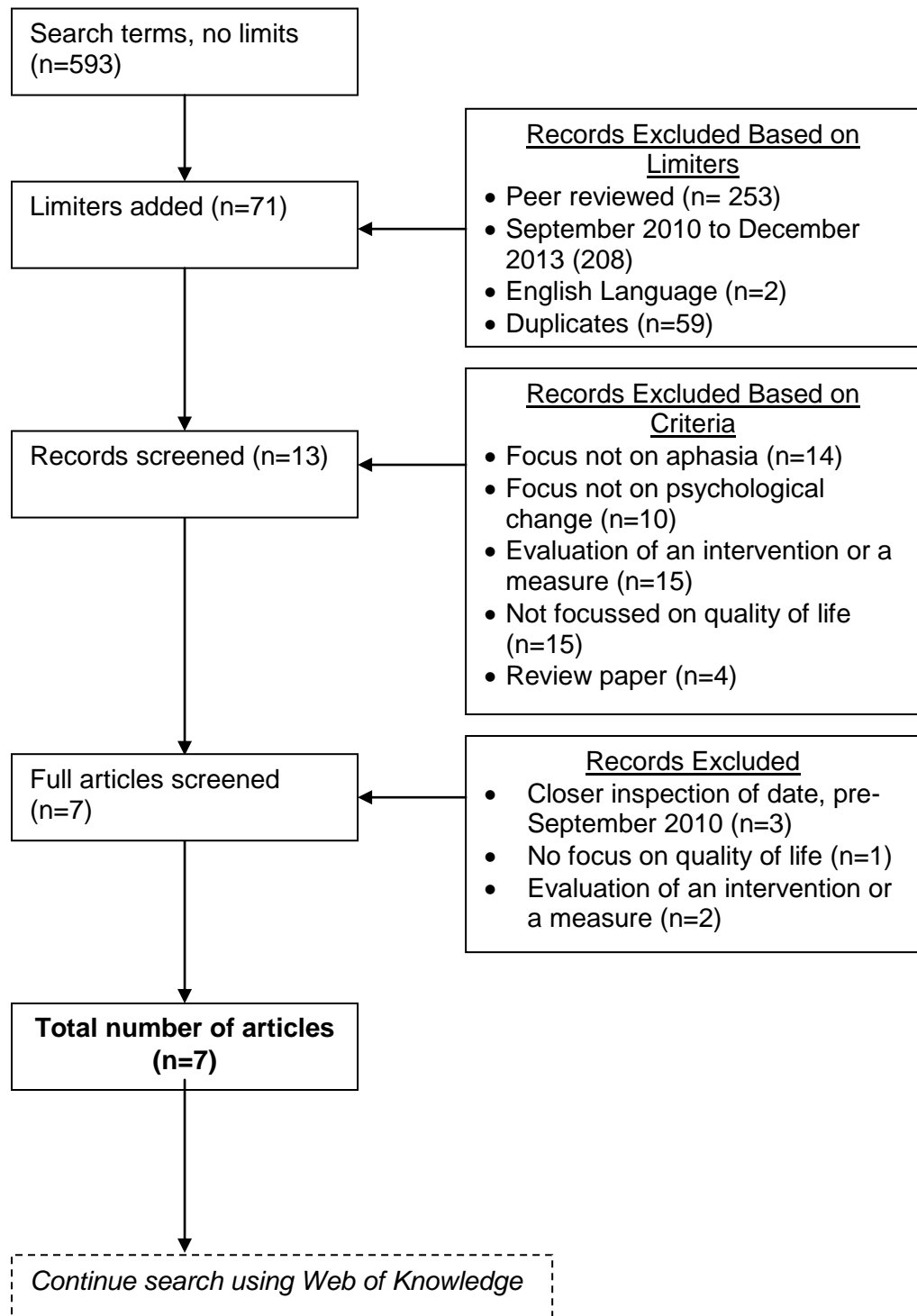
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Appendices

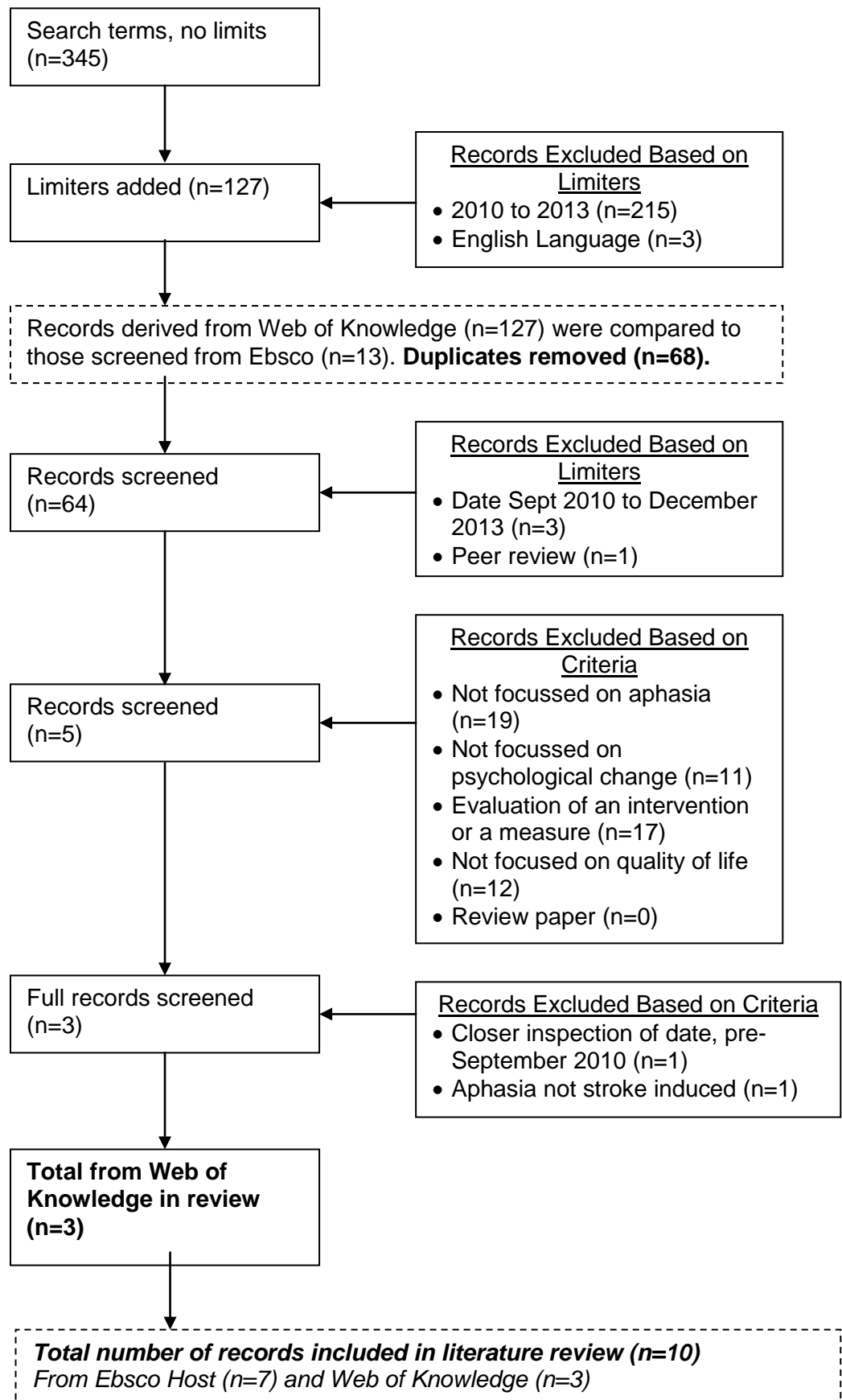
Appendix A

Flow diagrams to show how the 10 journal articles (records) were identified.

Appendix A1. Records found using Ebsco Host.



Appendix A2. Records identified using Web of Knowledge, combined with those identified from Ebsco Host.



Appendix B

Data Extraction Table

<i>Data Extraction Table</i>							
No.	Title, Authors and Date	Aims	Participants	Study Type/ Method	Key findings	Key Critique	Relevance to Quality of life Post-stroke and Aphasia
1	The First 3 – Months Post-Stroke: What Facilitates Successfully Living with Aphasia? Grohn, Worrall, Simmons – Mackie & Brown (2012)	Identify factors contributing to quality of life in the early stages of recovery, stroke and aphasia recovery	<ul style="list-style-type: none"> 15 people (7 female, 8 male) Up to 3 months post stroke and aphasia. Able to complete an interview Aged 47-90 years old. 	<ul style="list-style-type: none"> Cross-Sectional Mixed methods; semi structured interviews and questionnaires Data analysis: Thematic analysis 	5 themes: <ul style="list-style-type: none"> A need to do things Social support and relationships Rehabilitation Making adaptations and adjustments Positive outlook 	<ul style="list-style-type: none"> Small, biased sample – mildly aphasic, hand-picked by clinicians. Researcher, not participant terminated interviews when completed. Limited discussion of ethical issues. Supported communication not discussed Validity and reliability of the measures not reported. Rigor enhanced by multiple data analysts. No reflexivity discussion 	Five main factors identified to achieving a good quality of life in early stages of recovery, for people with mild aphasia.
2	Applying the Correlation Between Aphasia Severity and Quality of Life Measures to a Life Participation Approach to Aphasia. Williamson, Richman & Coyle Redmond (2011)	Investigate the correlation between aphasia severity and quality of life	<ul style="list-style-type: none"> 24 people (11 female, 13 male) Aged 22 - 81 years old. 11 months to 22 years post onset of stroke and aphasia. 	<ul style="list-style-type: none"> Cross-Sectional Quantitative; questionnaires Data analysis: correlation 	No relationship found between aphasia severity and Quality of life outcomes.	<ul style="list-style-type: none"> No power calculations to determine sample size Vague inclusion/ exclusion criteria and data collection. No mention of ethical issues or communication adaptations No consideration of confounding variables. Validity and reliability of measures discussed 	No link between quality of life and aphasia severity, adding to the mixed evidence-base. Rehabilitation services need to explore quality of life for stroke survivors with all levels of aphasia.

Quality of Life After Stroke and Aphasia

No.	Title, Authors and Date	Aims	Participants	Study Type/ Method	Key findings	Key Critique	Relevance to Quality of life Post-stroke and Aphasia
3	The Impact of Stroke: Are People with Aphasia Different to those Without? Hilari (2011)	Investigate activities of daily living, social support, psychological distress and HRQL in stroke survivors with and without aphasia in the first 6 months post-stroke.	<ul style="list-style-type: none"> 87 stroke survivors, 32 with aphasia, 55 without. Total sample, 35 female, 52 male, mean age 69.7. All levels of expressive and mild-moderate receptive aphasia Large exclusion criteria 	<ul style="list-style-type: none"> Cohort. Quantitative; questionnaires Data analysis used T tests, repeated measures ANOVA and Chi Squared test 	<ul style="list-style-type: none"> People with aphasia had a lower quality of life at onset and 3 and 6 months post-stroke. People with aphasia had higher levels of psychological distress at 3 months, but not 6 months. People with aphasia performed less activities of daily living over the 6 months, particularly social leisure and vocational activities. 	<ul style="list-style-type: none"> No power calculations to determine sample size Reasonable attrition rates Small sample of people with aphasia at 6 months (11 participants). Confounding variables were considered. Measures described, but validity and reliability was not reported. 	Aphasia contributed to the performance of fewer activities and a reduced quality of life. Psychological distress is common for stroke survivors with and without aphasia
4	Quality of Life and Post-Stroke Aphasic Syndromes. Sinanovic, Mrkonjic, & Zecic (2012)	Explore the impact of aphasia type and severity on quality of life	<ul style="list-style-type: none"> 51 people (23 male, 28 female) at least 1 year post-stroke and aphasia Aged 41-86 years. Excluded those scoring <7 on FAST receptive domains 	<ul style="list-style-type: none"> Cross sectional Quantitative; questionnaires Data analysis: ANOVA, Spearman's rho correlation 	<ul style="list-style-type: none"> People with aphasia had a lower quality of life in physical, communication, psychosocial and energy domains. Greater aphasia severity, lower quality of life. People with mixed, non-fluent and Broca's aphasia had the lowest quality of life. Those with Transcortical Sensory aphasia had the best. 	<ul style="list-style-type: none"> Included a range of aphasia severities and types. Confounding factors briefly considered No power calculations included, for the sample size No mention of any ethical issues No justification for use of parametric tests – no ANOVA f values stated. Measures discussed in detail, but no reference to validity or reliability. 	Further understanding of severity and type of aphasia on quality of life.

Quality of Life After Stroke and Aphasia

No.	Title, Authors and Date	Aims	Participants	Study Type/ Method	Key findings	Key Critique	Relevance to Quality of life Post-stroke and Aphasia
5	'Making a Good Time': The Role of Friendship in Living Successfully with Aphasia. Brown, Davidson, Worrall, & Howe (2013)	Explore perspectives about the role of friendship on living successfully with post-stroke aphasia	<ul style="list-style-type: none"> 25 people (12 female, 13 male) with post-stroke aphasia, at least 2 years post onset. Aged 38-86 years old. Mild to moderate/severe aphasia. 	<ul style="list-style-type: none"> Cross sectional. Qualitative: Semi structured interview Data analysis: Thematic analysis Quantitative questionnaire for demographic data 	3 overarching themes: <ul style="list-style-type: none"> Living with changes in friendship Good times together and support from friends The importance of stroke and aphasia friends 	<ul style="list-style-type: none"> Those who scored above the aphasia cut off on Western Aphasia Battery were included – biased sample. Thorough description of data collection and analysis Rigour of data analysis not discussed. No ethical considerations discussed. Unable to determine if participant's views were equally represented. Reflexivity issues not discussed. No report of validity or reliability measures used. 	To live successfully with aphasia, and to achieve a good quality of life, it is important to be aware that although friendships can change, or be lost, people with aphasia value friendships for companionship and support. Making new friends is important, particularly with others with post-stroke aphasia, via stroke groups.

Quality of Life After Stroke and Aphasia

No.	Title, Authors and Date	Aims	Participants	Study Type/ Method	Key findings	Key Critique	Relevance to Quality of life Post-stroke and Aphasia
6	The Lived Experience of Engaging in Everyday Occupations in Persons with Mild to Moderate Aphasia. Niemi & Johansson (2013)	Describe and explore how people with post-stroke aphasia engage in everyday occupations.	<ul style="list-style-type: none"> 6 people, 1-4 years post onset of stroke aphasia (3 male and 3 female) Aged 46-75 Inclusion criteria included the presence of mild/moderate post-stroke aphasia and an ability to answer open ended questions 	<ul style="list-style-type: none"> Cross sectional Qualitative: Semi structured interview Data analysis: Empirical Phenomenological Psychological analysis 	<p>Overarching themes:</p> <ul style="list-style-type: none"> Encountering new experiences in everyday occupations Striving to handle everyday occupations Going ahead with life 	<ul style="list-style-type: none"> Limited detail of aphasia assessment. Thorough coverage of ethical considerations and communication adaptations. Procedure was different for different participants – 3 participants were observed completing everyday activities in addition to the interview. Detailed description data collection and analysis methods. Findings subjected to participant and professional validation Reflexivity issues not discussed 	Completing activities is significant to achieve a good quality of life, in particular the social aspects, and the need to adapt activities to accommodate stroke symptoms. Leisure activities, those not reliant upon communication and everyday activities were important. Other factors were influenced by activities: self-esteem, frustration, social belonging, and a sense of progress /adaptation to stroke symptoms. Exploring the meaning and pertinence of different activities for people with post-stroke aphasia is vital.

Quality of Life After Stroke and Aphasia

No.	Title, Authors and Date	Aims	Participants	Study Type/ Method	Key findings	Key Critique	Relevance to Quality of life Post-stroke and Aphasia
7	Reporting on Psychological Wellbeing of Older Adults with Chronic Aphasia in the Context of Unaffected Peers. Cruice, Worrall & Hickson (2011)	Investigate the psychological wellbeing of older adults with post-stroke aphasia, compared to peers without stroke or aphasia.	<ul style="list-style-type: none"> 30 people with post-stroke aphasia (14 male, 16 female), mean age: 70.73 75 'unaffected' peers (28 male, 47 female), mean age: 73.85 years People with aphasia were at least 10 months post-stroke, had moderate comprehension and reliable yes/no response 	<ul style="list-style-type: none"> Case Control Quantitative measures Data analysis: T-tests and a correlation 	<ul style="list-style-type: none"> Participants with and without aphasia had similar wellbeing scores. People with aphasia seemed to have increased levels of depression, decreased independence and more physical difficulties than peers. 	<ul style="list-style-type: none"> Sample bias towards mild /moderate aphasia. Measures possibly insensitive differences in wellbeing between groups. Control group of people with stroke without aphasia would account for stroke being a confounding factor. The two groups were significantly different at baseline in age, education, mood and physical ability. Self-selecting control group, researcher-selected stroke group. Thus controls had to be motivated to partake, a trait possibly indicative of improved mood. No power calculations presented to determine sample size. Some discussion of reliability and validity of measures, but not reported for all questionnaires used. 	People with post-stroke aphasia experience higher levels of depression, which can impact negatively on quality of life. Communication and physical difficulties, and greater dependence on others, limits activity participation for people with post-stroke aphasia, leading to isolation, frustration and a requirement to adjust to a new sense of self accommodating stroke symptoms.

Quality of Life After Stroke and Aphasia

No.	Title, Authors and Date	Aims	Participants	Study Type/ Method	Key findings	Key Critique	Relevance to Quality of life Post-stroke and Aphasia
8	Living with Aphasia: Three Indigenous Australian Stories. Armstrong, Hayward, Fraser & Brown (2012)	Explore the experience of aphasia in Indigenous Australian Men	<ul style="list-style-type: none"> 3 Indigenous Australian men with post-stroke aphasia, at least 3 months post-stroke. Aged 47, 53 and 63 years old. 	<ul style="list-style-type: none"> Cross sectional Qualitative – semi structured interview Data analysis: thematic analysis 	<ul style="list-style-type: none"> Health difficulties were a greater concern than aphasia. Stroke at a young age can impact a number of areas: family, work and social life. All participants were satisfied with rehabilitation services. Important factors for quality of life were: family support, maintaining roles, community groups and activities, independence and being proactive in recovery. 	<ul style="list-style-type: none"> Interviewer was trained in effective communication skills. No formal assessment of aphasia, therefore unsure of the type or severity. Findings were subjected to participant validation Data analysis appeared to be a discussion rather than a thorough thematic analysis. Small participant sample in a very unique population – issues of generalisability Unclear why these 3 were chosen to partake, out of 10 eligible participants identified. 	Aphasia may not be the primary concern post-stroke, a number of factors seem to be important in achieving a good quality of life such as family support, community participation, independence, maintaining previous roles, proactively engaging in recovery.

Quality of Life After Stroke and Aphasia

No.	Title, Authors and Date	Aims	Participants	Study Type/ Method	Key findings	Key Critique	Relevance to Quality of life Post-stroke and Aphasia
9	Adjustment Processes in Chronic Aphasia After Stroke: Exploring Multiple Perspectives in the Context of a Community Based Intervention. Mumby & Whitworth (2013)	Explore perspectives about adjustment to aphasia processes	<ul style="list-style-type: none"> 3 people with post-stroke aphasia (2 male, 1 female, aged 40-70) 1 female carer, aged <60, 1 female volunteer aged <40 and 1 female council worker aged <50 Excluded people with severe aphasia Extra person with aphasia, (carer's husband) interviewed One participant died and was replaced. 	<ul style="list-style-type: none"> Cohort study Qualitative: semi-structured interviews Data analysis: grounded theory Quantitative: questionnaire s. Findings presented in appendix only. 	<ul style="list-style-type: none"> Quality of life is achieved through participation in activities, developing self worth and adjusting to aphasia. Overcoming barriers to quality of life involves: <ul style="list-style-type: none"> Finding new, and adapting activities Gradual change from negative to positive emotions, aided by determination, recovery reflection and finding meaning in experiences, leading to increased independence, enjoyment, hope, looking to the future, openness, an understanding of others, and a sense of worth and acceptance. Support to reintegrate in social activities and ADLs and involvement in relationships. Raising awareness and improving aphasia accessibility within organisations and personalised, aphasia friendly information. 	<ul style="list-style-type: none"> The key findings were not clear or succinct. Potential sample bias, as they were recruited from a community intervention for people with aphasia, raising issues of generalisability. Results were subjected to professional validation 	Barriers to achieving a good quality of life and means of overcoming these obstacles were identified.

Quality of Life After Stroke and Aphasia

No.	Title, Authors and Date	Aims	Participants	Study Type/ Method	Key findings	Key Critique	Relevance to Quality of life Post-stroke and Aphasia
10	Social Participation Through the Eyes of People with Aphasia. Dalemans, de Witte, Wade & van den Heuvel (2010)	To explore how people with post-stroke aphasia view their social participation, and the factors that impact this.	<ul style="list-style-type: none"> 13 people with aphasia (6 female, 7 male, aged 45-71 years), between 1 to 11 years post-stroke. Stroke survivors experienced a range of aphasia severity, but type of aphasia was not reported. 11 spouses and 1 daughter also recruited. 	<ul style="list-style-type: none"> Cross sectional Qualitative: semi structured interviews, diaries and a focus group Quantitative: measures for aphasia severity 	<ul style="list-style-type: none"> Opportunities for social involvement reduced post-stroke, including work. A desire for more community involvement. People with aphasia felt isolated, with conversation being hard and dominated by others. Stroke survivors withdrew from activities so that they did not burden others, and felt that they were not respected by others Quality rather than quantity of social participation was important. <ul style="list-style-type: none"> Factors influencing social participation are personal, social and environmental in nature 	<ul style="list-style-type: none"> Ethical aspects considered in depth. Use of communication aids encouraged Small sample of participants Aphasia-friendly diaries used to guide interviews. Their use could have biased/ restricted the information brought to the interview. Findings subjected to professional and participant validation 	Although not directly linked to quality of life, a number of factors related to social participation, which is known to impact quality of life, are identified. The negative impact of aphasia on socialising with others, and the resulting feelings of isolation were discussed. People with aphasia reduced their participation in activities, so that they did not feel burdensome. Fewer activities can lead to a lower quality of life.

Quality of Life After Stroke and Aphasia: Stroke Survivors' and Spouses' Perspectives

Abstract

Background: Stroke primarily occurs in older adults, and as the UK population is ageing, it is likely to affect more people in coming years. About a third of stroke survivors experience aphasia as a result of stroke. Clinical psychologists are required to be part of the stroke rehabilitation teams, thus an understanding of what contributes to a good quality of life for this population is paramount to provide effective therapeutic interventions. The paucity of the current quality of life post-stroke and aphasia evidence base has been acknowledged by a number of authors. Reasons for this include the use of biased samples, inconsistent outcome data and unclear inclusion criteria. The main concern was the relatively aphasia-unfriendly data collection methods used to date, primarily questionnaire, interview and proxy report methods. It has therefore not been possible to conclude with confidence what factors are important to achieve a good quality of life post-stroke and aphasia.

Aims: Q methodology was deemed to be an appropriate, aphasia-friendly method of obtaining the views of aphasic stroke survivors and their spouses, regarding what factors contribute to a good quality of life. Participants completed a Q sort task, in which they ranked a number of statements, depicting different factors that could influence quality of life, in terms of their personal importance. Spouses were asked to complete the task from the perspective of the stroke survivor. Altogether, six aphasic stroke survivors and five spouses took part. Questionnaires to assess the stroke survivors' communication ability, mood and ability to complete activities of daily living, were completed. Data was analysed using PQMethod software.

Outcomes & Results: Significant, positive and strong pair-wise correlations between the Q sort outcomes of the stroke survivors' and their respective spouses' confirmed that spouses could reliably report factors important to quality of life on behalf of their aphasic partner. Two

overarching factors, important to achieving a good quality of life were identified: 'returning to the pre-stroke self' which primarily represented the stroke survivors of working age, and 'life beyond stroke, what's important now?' which mainly reflected the views of the older, retired participants. The factors were considered in relation to Erikson's (1968) psychosocial stages of development model and in terms of stroke recovery models (Holbrook, 1982; Kirkevold, 2002).

Conclusions: Different factors may be important to aphasic stroke survivors, at different points in their life, and at different stages of their stroke recovery. This is useful to understand when working as a clinical psychologist in stroke rehabilitation services, to be able to tailor therapeutic interventions appropriately, particularly if communication difficulties introduce challenges in determining such values. The importance of tailoring therapy to the individual was also highlighted, as not all participants shared the views of the factors identified. Q methodology was a suitably aphasia-friendly method of obtaining the stroke survivors' viewpoints, thus showing that this population can successfully be involved in research. The Q sort is akin to communication aids currently used by speech therapists, and could be used in this way during psychological assessment and intervention with people with aphasia. Lastly, spouses could reliably report the factors important to quality of life on behalf of their aphasic partners.

Key words: Aphasia, Stroke, Quality of Life.

Introduction

Stroke, Aphasia and Quality of Life

Stroke affects about 150,000 each year in the UK, primarily those aged >65 years (Stroke Association, n.d.). The UK population is ageing (Office for National Statistics, 2012) and therefore stroke is likely to affect a larger proportion of people, and rehabilitation services need to provide adequate and evidenced based healthcare. Recent guidance from the National Institute for Health and Care Excellence (NICE; 2013) details the need for long-term rehabilitation post-stroke, stating the involvement of clinical psychologists in the stroke multidisciplinary team,

to assess and support individuals with subsequent cognitive and emotional difficulties.

Stroke can cause of a variety of physical, psychological and cognitive symptoms (Willacy, 2012), with 21-38% of stroke survivors experiencing the communication disorder, aphasia (Berthier, 2005). Six known types of aphasia exist: Broca's, Wernicke's, Conduction, Transcortical Sensory and Global aphasia, in addition to Anomia, (word finding difficulties), which encapsulate the different language difficulties the stroke survivor may experience. Aphasia type is largely dependent on the location and the extent of damage to the brain caused by the stroke, and the interruption to the blood and oxygen supply. Individuals can experience difficulties in both expressing and understanding language, and reading and writing (Lincoln, Kneebone, Macniven and Morris, 2012).

Quality of life is multi-faceted and is known to be impacted by a number of factors. Stenner, Cooper and Skevington, (2003) define quality of life as 'one's perception of their position in life, within the context of their culture and value systems, in relation to goals, expectations, standards and concerns, influenced by physical health, psychological state, level of independence, social relationships, relationships to the environment and comprising spiritual, religious and personal beliefs.' (p. 2161). Stroke and aphasia could therefore impact someone's quality of life, and a role of the psychologist in the MDT would be to aid adjustment to the sudden life changes, and to regain quality of life. Numerous psychological theories address the concept of quality of life. An acceptance and commitment therapy approach emphasises achieving a mindful, meaningful and values congruent way of life (Harris, 2009), the hierarchy of needs model (Maslow, 1970) suggests that humans strive to attain self actualisation having met their physiological, safety, attachment, esteem, cognitive and aesthetic needs. Rogers (1961) suggests that self actualisation leads to quality of life, but is experienced through receiving unconditional positive regard, exempt from conditions of worth, and developing a positive sense of self (Carlson, Martin, and Buskist, 1997). Finally, according to Erikson's

(1963) psychosocial stages of development model, at each life stage, people must successfully resolve a social dilemma to achieve a good quality of life. Adulthood comprises three stages: (a) intimacy versus isolation (aged 18 to 40 years old), (b) generativity versus stagnation (aged 40 to 65 years old) and (c) ego integrity versus despair (aged 65 years and above). Successful completion of these stages includes achievements such as developing a safe and caring relationship, contributing to society through working, child rearing or community involvement, and on retirement, an ability to reflect upon life with a sense of achievement and satisfaction. Unsuccessful completion of the stages can lead to poor quality of life, with feelings of isolation and loneliness, unproductivity or guilt, or feelings of despair (Carr, 2007; McLeod, 2008).

Current Stroke, Aphasia and Quality of Life Literature

The main factors impacting health related quality of life (HRQL) have been summarised in Hilari, Needle and Harrison's (2012) systematic review of the relevant literature. Factors limiting HRQL included: emotional distress/ depression, severity of aphasia, medical problems, poor body functioning, activity restrictions, the stroke, mobility difficulties and older age. Factors improving HRQL were: completing activities, having goals and a positive outlook, taking charge of communication rehabilitation, being independent and in one's own home, satisfaction with social network and social support, particularly to meet informational and companionship needs, developing new personal and collective (with others with aphasia) identities, educating others about aphasia and provision of aphasia-accessible information.

Hilari *et al.* (2012) concluded that the design and quality of the research included in the review was of an inadequate standard to enable firm conclusions to be made regarding predictors of HRQL post-stroke and aphasia. Primary concerns were the lack of, or inadequate use of regression analysis, the rare use of longitudinal designs, high attrition rates, missing or inconsistent outcome data, participant sample

biases, unclear inclusion criteria, omission of details regarding saturation of data and rigour of findings.

Subsequent research confirms Hilari *et al.*'s (2012) findings regarding factors impacting quality of life, and continue to highlight quality issues about the existing research. Additional problems identified include the lack of research involving people with stroke and aphasia, inadequate descriptions of aphasia severity and type and an over-reliance upon proxy reports. (Armstrong, Hayward, Fraser & Brown, 2012; Brown, Davidson, Worrall, & Howe, 2013; Cruice, Worrall & Hickson, 2011; Dalemans, de Witte, Wade & van den Heuvel, 2010; Grohn, Worrall, Simmons–Mackie & Brown, 2012; Hilari, 2011; Mumby & Whitworth, 2013; Niemi & Johansson, 2013; Sinanovic, Mrkonjic, & Zecic, 2012; Williamson, Richman, & Coyle Redmond, 2011). Further still, there are fundamental issues with the validity of data collection methods used with people with communication difficulties.

Qualitative studies have used semi structured interviews (Armstrong, *et al.*, 2012; Brown *et al.*, 2013; Brown, Worrall, Davidson, Howe, 2010; Cruice, Hill, Worrall and Hickson, 2010; Dalemans, de Witte *et al.*, 2010; Grohn *et al.*, 2012; Mumby and Whitworth, 2013; Niemi and Johansson, 2013; Parr, Byng, Gilpin, Ireland, 1997), which has strengths: individual views about the subjective experience of quality of life and viewpoints beyond those of the researcher can be obtained, opinions can be explored in depth, and interviews can be complimented by other data collection methods, e.g. videos, photographs and diaries (Brown *et al.*, 2010; Cruice *et al.*, 2010; Dalemans *et al.*, 2010). However, this method may not be suitable for people with communication difficulties who may find understanding questions or verbally expressing answers problematic, particularly if open questions, requiring in-depth answers are required.

Quantitative research predominantly uses questionnaire data collection methods (Bose, McHugh, Schollenberger and Buchanan, 2009; Cruice *et al.*, 2011; Grohn *et al.*, 2012; Hilari, 2011; Hilari and Byng, 2009; Hilari and Northcott, 2006; Hilari, Wiggins, Roy, Byng and Smith, 2003; Hinckley, 1998; Mumby & Whitworth, 2013; Ross and

Wertz, 2002; Sinanovic *et al.*, 2012; Williamson *et al.*, 2011), again, which people with aphasia may find difficult to engage with, particularly when having to read and understand items and when providing verbal or written responses. More recent studies (Bose *et al.*, 2009; Hilari and Byng, 2009; Hilari and Northcott, 2006; Hilari *et al.*, 2003; Mumby and Whitworth, 2013; Sinanovic *et al.*, 2012; Williamson *et al.*, 2011) use aphasia friendly questionnaires such as the Stroke and Aphasia Quality of Life – 39 scale (SAQOL-39; Hilari and Byng, 2001) or have adapted existing questionnaires to make them aphasia-accessible (Cruice, *et al.*, 2011). The inappropriateness of using questionnaires to collect information about the subjective concept of quality of life has also been raised. The term ‘quality of life’ and the questionnaire items addressing this will have a different meaning to each person, which may not be captured by the questionnaire. Questionnaire design may also reflect the researchers’ values, beliefs, clinical experience or knowledge, and therefore may not gather information unique to the participants (Rosenberg, 1995; Stenner, Cooper and Skevington, 2003).

Another concern is that of proxy reports, and the mixed evidence regarding the validity of this method. Evidence exists to suggest that proxy reports are not an accurate representation of stroke survivors’ views (Bose *et al.*, 2009; Cranfill and Wright, 2010), but that accuracy may be increased if reporting on more concrete or specific matters, (Cruice, Worrall, Hickson and Murison, 2005; Sneeuw, Sprangers and Aronson, 2002). Other research indicates otherwise, that although more problems may be identified, proxies can give a fairly accurate account on behalf of aphasic stroke survivors (Hilari, Owen, and Farrelly, 2007; Ignatiou, Christaki, Chelas, Efstratiadou and Hilari, 2012). Presently, proxy reports may be the only means of determining factors affecting quality of life for people with severe receptive aphasia, thus clarification on their accuracy is paramount.

Due to design and methodological difficulties demonstrated in previous research, there is a lack of good quality evidence about what factors may help people with aphasia to maintain a good quality of life post-stroke. Furthermore, the reliability of proxy reports is unknown, due

to mixed findings as discussed. It is therefore important to conduct further research to address both of these issues. The present study proposes the use of Q Methodology (Stephenson, 1935) involving aphasic stroke survivors and their spouses, to overcome such issues, thus enabling quality of life for this population to be investigated effectively.

Q Methodology

Q methodology has been used to assess factors affecting quality of life in healthy participants (Stenner, Cooper and Skevington, 2003) but not with aphasic stroke survivors. Q Methodology determines similarities and differences between subjective views of a homogeneous group of people. Viewpoints are gathered through the completion of a Q sort task, requiring participants to rank a set of stimulus items/ statements (Q set) in relation to each other and to a psychologically significant scale, in answer to a particular question. The completed Q sort is required to resemble a normal distribution, thus an element of forced choice is incorporated. Completed Q sorts represent participants' viewpoint as a whole. Factor analysis compares the Q sorts and produces factors which represent subgroups of participants sharing similar perspectives. Interpretation of factors provides a collective understanding of participant's views. Each Q sort is correlated with each other Q sort, enabling the identification of pairs of participants sharing similar views.

Q methodology has the potential to be aphasia-friendly; it is less reliant upon communication ability compared to interview and questionnaire methods, not requiring verbal or written responses. The Q sort task is akin to communication aids currently used by speech and language therapists (SALTs) (Talking Mats, n.d.). The standard Q sort can be adapted to enhance its accessibility; the Q set statements can be written in short and simple sentences, large font, with key words emboldened (Hilary and Byng, 2001). With a knowledge of the participant's language ability, the Q sort administrator can adapt their communication style (e.g. use of repetition and rephrasing) and use

additional communication aids (e.g. response cards, pen and paper) to support the participants' comprehension and completion of the task.

The aims of the current study are therefore to:

- Use Q methodology to determine what factors are important in achieving a good quality of life, post-stroke and aphasia, from the perspectives of aphasic stroke survivors and their spouses, via the completion and analysis of Q sorts.
- Create and use an adapted, aphasia-friendly Q sort to gather such information. Inspiration for the development of the Q set will be derived from advice from people with post-stroke aphasia and speech and language therapists (SALTs), the current research evidence base, and the author's knowledge from previous experience.
- Determine the reliability of proxy reports about the factors impacting quality of life after stroke and aphasia, by asking spouses to complete the Q sort from the perspective of their aphasic partner, and comparing the outcomes for similarity.

Method

Approvals

Ethical approval was attained from the sponsor, Staffordshire University (Appendix A1), and from the NHS East of Scotland Research Ethics Service (Appendix A2). R&D approvals were sought from Nottinghamshire County Health Partnerships and Nottingham City Care (Appendix B). Subsequent amendments received approval from the appropriate bodies (Appendix A and B).

Design and Methodology

A cross sectional design was used (Coolican, 2009) in conjunction with Q methodology (Stephenson, 1953).

Materials. Prior to completing the Q sort task, the required materials were developed.

Q Set. A structured approach was used to create the 49 statements forming the Q set. A general search of the literature regarding quality of life post-stroke and aphasia was conducted,

identifying 13 broad factors: communication, health, emotions, family and friends, not understanding aphasia, activities, identity, positive outlook, roles, goals for the future, home, independence, and support from services. These factors were presented, via an aphasia-friendly power point presentation (Hilari and Byng, 2001), to a group of aphasic stroke survivors, facilitated by SALTs. Feedback about the factors and their relevance was requested, using prompts such as 'what makes life better/ worse?' 'What is helpful/ not helpful?' And 'what is important/ not important?' to generate discussion. The factors were deemed to be very broad, but encapsulated the main areas regarding quality of life.

Subsequently, a structured and in-depth review of the literature was completed. An amalgamation of the researcher's knowledge from prior research experience, feedback from the group, and an extensive review of the literature informed the content of the Q set statements.

Statements were designed to be aphasia-friendly, using size 14 font, emboldened key words and short, simple sentences and pictures to facilitate comprehension (Appendix C). To enhance rigour, the statements were presented to the clinical and research supervisors overseeing the study, and to a SALT, for confirmation that the content and presentation of the statements was appropriate.

Distribution Grid. A distribution grid, incorporating a scale was constructed to aid participants ranking of the Q set statements (Figure 1). The grid was presented on pale yellow card, the size of two A1 sheets. Spaces indicating where statement cards should be placed were outlined in black, and were arranged according to a standard distribution. In the spaces, and on the back of the statement cards, were patches of Velcro, for ease of allocation. The scale ranged from most unimportant (-5) to 0 to most important (+5).



Select

Inclusion and Exclusion Criteria. Participants were invited to

Con

D3), to accommodate individual communication difficulties, and a home visit was arranged accordingly. Prior to the visit, a supervisor was informed of the location and anticipated duration, and was contacted on completion, to ensure safety of the researcher. During the first visit, the study was explained using the participant information sheet (Appendix D2), and the aphasia friendly participant information sheet (Appendix E), derived from those used by Thomas, Walker, Macniven, Haworth and Lincoln (2013). Subsequently consent forms (Appendix F) were completed with individually with the stroke survivor and their spouse.

Questionnaires. Following consent, the FAST was carried out with the stroke survivor (Appendix G1). If a score of $\geq 7/15$ on the receptive domains was achieved (Hilari, 2011), questionnaires to assess mood, daily activities and physical abilities were conducted. The 'Sad' Visual Analogue Mood Scale (VAMS; Stern, 1996) was completed with the stroke survivor (Appendix G2) whilst their spouse filled in the Stroke and Aphasia Depression Questionnaire – Hospital 10 (SADQ-H10; Lincoln, Sutcliffe and Unsworth, 2000) (Appendix G3). The Bartel Index (Wade and Collin, 1988) (Appendix G4) and Nottingham Extended Activities of Daily Living (NEADL; Nouri and Lincoln, 1987) (Appendix G5) were completed with input from both participants to assess the stroke survivor's engagement and capabilities in conducting activities of daily living. A second home visit was arranged to carry out the Q sort.

Q Sort. The Q sort was conducted with the stroke survivor and their spouse, separately. Participants were introduced to the materials and the task, and given a set of instructions comprising the points listed in Figure 2.

Figure 2. Q Sort Instructions

- Each card shows a statement about something that might be important to achieve a good quality of life, since having the stroke and subsequent communication difficulties.
- Each statement is required to occupy a space on the grid, according to their personal importance, and in relation to each other, starting with those most important (+5) through to those that are least important (-5), using the scale provided.
- The statements placed in the middle of the grid may represent those that they feel indifferent about, that are neither important nor unimportant, those that they are unsure about, or those that are subject to change.
- Ranking a statement with a minus number would not necessarily mean that they disagreed with the content, but that it was somewhat less important than other statements.
- Only two statements can be placed in the +5 and -5 columns, three in the +4 and -4 columns and four in the +3 and -3 columns, and so on and so forth.
- The order in which statements are placed within each column is irrelevant.

Figure 2. Q sort instructions. This figure displays the instructions given to participants prior to completing the Q sort task (Watts and Stenner, 2012).

Participants were required to place each of the 49 statements into one of three piles, labelled 'important,' 'neutral,' and 'unimportant.' The spouse worked through this task independently, whilst the stroke survivor and researcher discussed each statement, to ensure understanding of the Q set. All participants displayed a sorting bias towards the 'important' category. These statements were further broken down into categories of 'more important,' 'neutral' and 'less important.' Participants placed the statements onto the grid, firstly by identifying the two most important statements and allocating them to the +5 spaces, then proceeding to the +4 column, and +3 until all of the 'important'

statement cards had been allocated. Participants identified the two least important statements, and placed them on the -5 column, and then added the remaining 'unimportant' statements to the grid. The final statement cards were placed in the middle of the grid, until all spaces were filled. Once finished, participants viewed and altered their Q sort until they were satisfied with its accuracy. Participants were asked questions about their experience of the task (Figure 3). Photographs of the Q sorts were taken to record the data.

Figure 3. Participant questions

- How did you find completing the task?
- Why did you allocate those statements to the +5 and -5 columns? What is their meaning and why are they important or unimportant?
- Were there any statements that you didn't understand?
- Were there any statements that were difficult to place?
- Were there any statements that were missing? If so what would you name this?

Figure 3. Participant Questions. Figure 3 shows the questions asked of participants to obtain feedback on the completion of the Q sort task.

Ethical Considerations

Comprehension. As aphasia can impact an individuals' language comprehension (Lincoln *et al.*, 2012), appropriate measures were implemented to ensure that participants understood the study requirements. An Aphasia-friendly information sheet (Appendix E) was used to aid understanding of the study, which included 'yes/no' response cards to support those with expressive difficulties to convey their decisions (Thomas *et al.*, 2013). The researcher used the Mental Capacity Act (2005) principles when necessary. Use of the FAST identified overall severity of aphasia and the domains of impairment, so the researcher could identify suitable communication aids and adapt communication accordingly. It was deemed, based upon previous

research (Hilari *et al*; 2001, 2009, 2003) that those with severe comprehension problems, scoring <7 on the FAST receptive domains, would find the Q sort task too difficult.

Confidentiality. All participant identifiable data was stored in a locked cupboard, dedicated to clinical research, at the University of Nottingham. Data analysis used anonymous data, the outcomes of which were stored on an encrypted and password protected memory stick.

Minimising Distress. Contemplating quality of life post-stroke could have been distressing to participants. Safeguards were therefore introduced. The researcher used clinical skills to identify and mediate distress, provided contact details of sources support (Appendix H) and liaised with the referring SALTs if there were concerns about participants' wellbeing.

Reflexivity

The researcher was a white, British female, aged late 20s, with no personal experience of living with stroke or aphasia, but had worked for two years in a research team investigating the impact of stroke and aphasia on individuals. Knowledge gained from this experience influenced the location, the supervisors and clinicians involved and the design and the development of materials used.

The researcher's philosophical stance was informed by social constructionist views. Q methodology lends itself to a social constructionist viewpoint (Darlaston-Jones, 2007; Watts and Stenner, 2012). Quality of life was considered to be an individual experience, influenced by factors in the wider context. The Q sorts gathered unique views and the interpretation of collective Q sorts determined the dominant social beliefs.

Results

Participant Characteristics

Consort Diagram. Figure 4 encapsulates participant recruitment. Two couples withdrew prior to the initial visit, having further considered the study and deciding not to participate. One couple

withdrew prior to consenting; the stroke survivor found it challenging to comprehend the requirements and did not wish to progress. Stroke survivor and spouse 05 withdrew after questionnaire completion due to illness, and spouse 04 withdrew after completing half of the Q sort, having found the task difficult and time consuming, and therefore not wishing to continue. Eleven participants; six stroke survivors and five spouses completed demographic questionnaires and the Q sort task.

Figure 4. Consort diagram

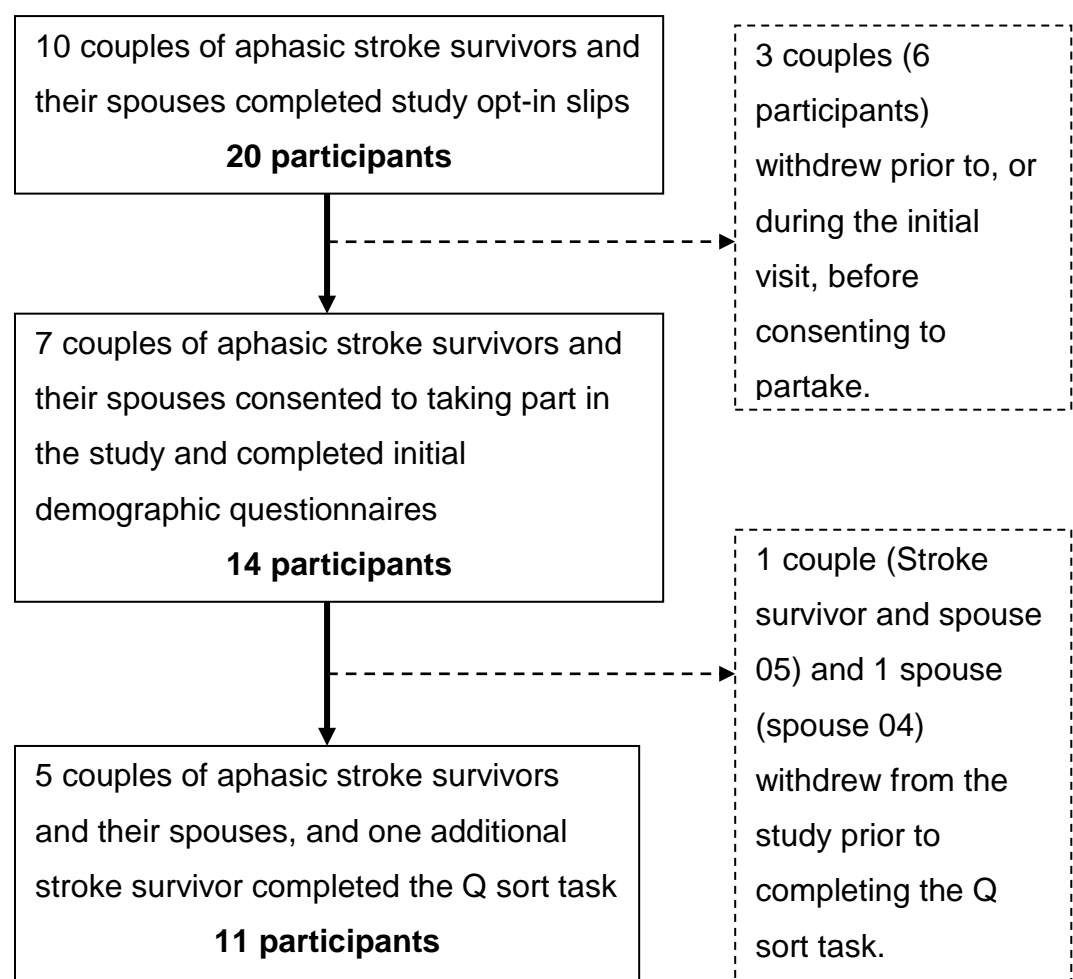


Figure 4. Consort diagram. This figure shows the recruitment and attrition of participants throughout the study

Demographics. Table 1 displays demographic information gathered via the demographic questionnaire (Appendix I). Six participants were aphasic stroke survivors; four male and two female, with an age range of 50 to 71 years old (average 62.3 years) and five

were spouses; two male and three female, with an age range of 54 to 73 years old (average 63.6 years). The stroke survivors had known their spouses between 18 to 55 years (average 36.5 years) and five out of the six stroke survivors were married. All participants were British. Five participants were retired (three stroke survivors and two spouses). One stroke survivor was unable to work, and their spouse became their carer. Two stroke survivors remained employed, but were not working; one of their spouses continued to work full time and the other was unemployed.

Table 1

Demographic Information of Stroke Survivors (SS) and Spouses (S)

ID	<u>Gender</u>		<u>Age (Years)</u>		<u>Employment Status</u>		Known (Years)
	SS	S	SS	S	SS	S	
01	M	F	70	68	Retired	Retired	53
02	F	M	71	73	Retired	Retired	55
03	M	F	57	54	Unable to work	Carer	35
04	M	N/A	69	N/A	Retired	N/A	39
06	F	M	50	63	Statutory Sick Pay	Full Time Employment	18
07	M	F	57	60	Employed, not working	Unemployed	19

Note. Gender: Male (M) and Female (F).

Stroke Details. Table 2 displays stroke specific information. Time post-stroke ranged from 2 to 30 months (average 13.3 months). Limited information regarding the stroke type and severity was attained, as participants rarely knew this detail. The strokes predominantly occurred in the left hemisphere, consistent with neuroanatomy reports, that this is the location of the language centres, Broca's and Wernicke's areas. Damage to these regions and associated connections result in aphasia (Banich, 2004). Stroke rehabilitation support varied between participants. Some received only SALT input, whereas others received a combination of occupational therapy, physiotherapy and psychology. NICE guidance (2013) encourages the involvement of a MDT in stroke rehabilitation.

Table 2

Stroke Details

ID	Months Post Stroke	Stroke Type	Stroke Location	Health Care Support
01	16	Ischemic	Left (uncertain)	SALT, PT, OT, Community Doctor, Mental Health Nurse, Orthotics
02	2	Haemorrhagic	Left	SALT, OT
03	20	Unknown	Both	SALT
04	30	Unknown	Unknown	SALT, Doctors, Exercise for Life Programme
06	8	Total Anterior Circulation	Left	SALT, PT, OT, Psychologist,
07	4	Unknown	Left	Previously: ESD (SALT, OT PT,). Currently: SALT Awaiting: PT, OT.

Note. Speech and Language Therapist (SALT), Occupational Therapy (OT), Early Supported Discharge (ESD), Physiotherapy (PT)

Activities of Daily Living. The NEADL assessed the ease with which participants completed mobility, kitchen, domestic and leisure activities. Reliability, validity and use of the NEADL is documented (Nouri and Lincoln, 1987; Gladman, Lincoln and Adams, 1993; University of Nottingham, n.d). High scores indicate greater independence. Table 3 shows that participants' scores ranged from 4 to 20 out of 22 (average 13.3), thus some stroke survivors completed few activities, and some completed all of those listed. Scores may reflect extent of physical ability, self confidence or extent of spouse involvement in completing activities. The Bartel Index evaluated the ability to complete more fundamental, personal care activities, with higher scores suggesting a higher level of functioning. Construct validity (Gosman-Hedstrom and Svensson, 2000; Wade and Hewer, 1987), and test-retest and inter-rater reliability (Wolfe, Taub, Woodrow and Burney, 1991) have been confirmed. Table 3 shows that the scores ranged from

14 to 20, out of 20 (average 18.3) suggesting that participants showed limited disability in performing basic ADLs.

Mood. The VAMS is a pictorial questionnaire allowing the stroke survivor to indicate their mood state. Test-retest reliability (Arruda, Stern, Somerville and Bishop, 1997) and content (Stern, Arruda, Hooper, Wolfner and Morey, 1997), convergent and discriminate validity (Stern, 1997) have been documented. A higher score indicates a lower mood. Table 3 shows that participants' scores ranged from 0 to 47, out of 100 (average 19.2), thus their self-reported mood was fairly neutral. The SADQ-H10 gathers proxy views regarding the stroke survivor's mood. Reliability and validity has been reported (Cobley, Thomas, Lincoln and Walker, 2012). Higher scores indicate higher levels of depression. Spouses completed the SADQ-H10. The scores ranged from 2 to 6, out of 30 (average 3.7), suggesting that stroke survivors displayed minimal visible signs of depression, in agreement with the self-report VAMS scores (Table 3).

Table 3

Stroke Survivors' Mood and Activity of Daily Living Scores

ID	NEADL (/22)	VAMS (/100)	SADQ-H10 (/30)	Bartel Index (/20)
01	13	11	3	18
02	15	47	6	20
03	9	0	3	18
04	20	20	4	20
06	19	37	4	20
07	4	0	2	14

Note. Activity of Daily Living measured by Nottingham Extended Activities of Daily Living (NEADL) and Bartel Index. Mood measured by Visual Analogue Mood Scale (VAMS) and Stroke Aphasic Depression Questionnaire-Hospital10 (SADQ-H10)

Communication Abilities. The FAST assessed four areas of communication; comprehension and reading (receptive domains) and expression and writing (expressive domains). Construct and criterion validity (Al-Khawaja, Wade, and Collin, 1996; Enderby and Crow, 1996) and test-retest and inter rater reliability (Enderby, Wood, Wade, and

Langton Hewer, 1987; Philip, Lowles, Armstrong, and Whitehead, 2002; Sweeney, Sheahan, Rice, Malone, Walsh, and Coakley, 1993) have been established.

SALTs confirmed the presence of aphasia on referral and all participants met the FAST criteria for presence of aphasia (Aged ≤ 60 years; <27 , aged ≥ 61 years; <25). Table 4 shows participants' FAST scores in each communication domain. Higher scores indicate greater communication ability.

All participants scored ≥ 7 on the receptive domains of the FAST and were eligible to complete the Q sort task. Stroke survivor 03 achieved a score of 7, with repetition of questions. This support enhanced their comprehension, and was available during the Q sort, thus they remained in the study. Participant's total scores on the receptive domains ranged from 7 to 13 out of 15 (average 9.8). Comprehension scores ranged from 5 to 8, out of 10 (average 6.3), and reading scores ranged from 2 to 5, out of 5 (average 3.5).

Participant's total scores on the expressive domains ranged from 2 to 12, out of 15 (average 8.0). Verbal expression scores ranged from 2 to 8, out of 10 (average 6.2), and writing scores ranged from 0 to 4, out of 5 (average 1.8).

Table 4

Stroke Survivors' Frenchay Aphasia Screening Test Scores

<u>Participant Details</u>		<u>FAST Receptive Domains</u>			<u>FAST Expressive Domains</u>			<u>FAST Total</u>
ID	Age	<i>Comprehension</i> (/10)	<i>Reading</i> (/5)	<i>Total</i> (/15)	<i>Expression</i> (/10)	<i>Writing</i> (/5)	<i>Total</i> (/15)	
01	70	6	4	10	6	0	6	16
02	71	6	2	8	6	3	9	17
03	57	5	2	7	8	0	8	15
04	69	8	5	13	7	4	11	24
06	50	7	4	11	8	4	12	15
07	57	6	4	10	2	0	2	12

The FAST is a screening tool, not a thorough assessment of language ability, thus detailed descriptions of aphasia type and severity were not determined. The FAST was adequate for the purpose of the study, to assess participants' eligibility/ ability to complete the Q sort task, and to establish appropriate communication aids. Informal discussions with participants in conjunction with FAST scores implied that the level/ type of aphasia of this sample ranged from mild to severe expressive aphasia, and mild to moderate receptive aphasia. Those with severe receptive aphasia were not referred to the study. Figure 5 shows the stroke survivors' FAST expressive and receptive scores, providing graphical representation of individual communication strengths and difficulties.

Figure 5. Stroke survivors' FAST expressive and receptive scores

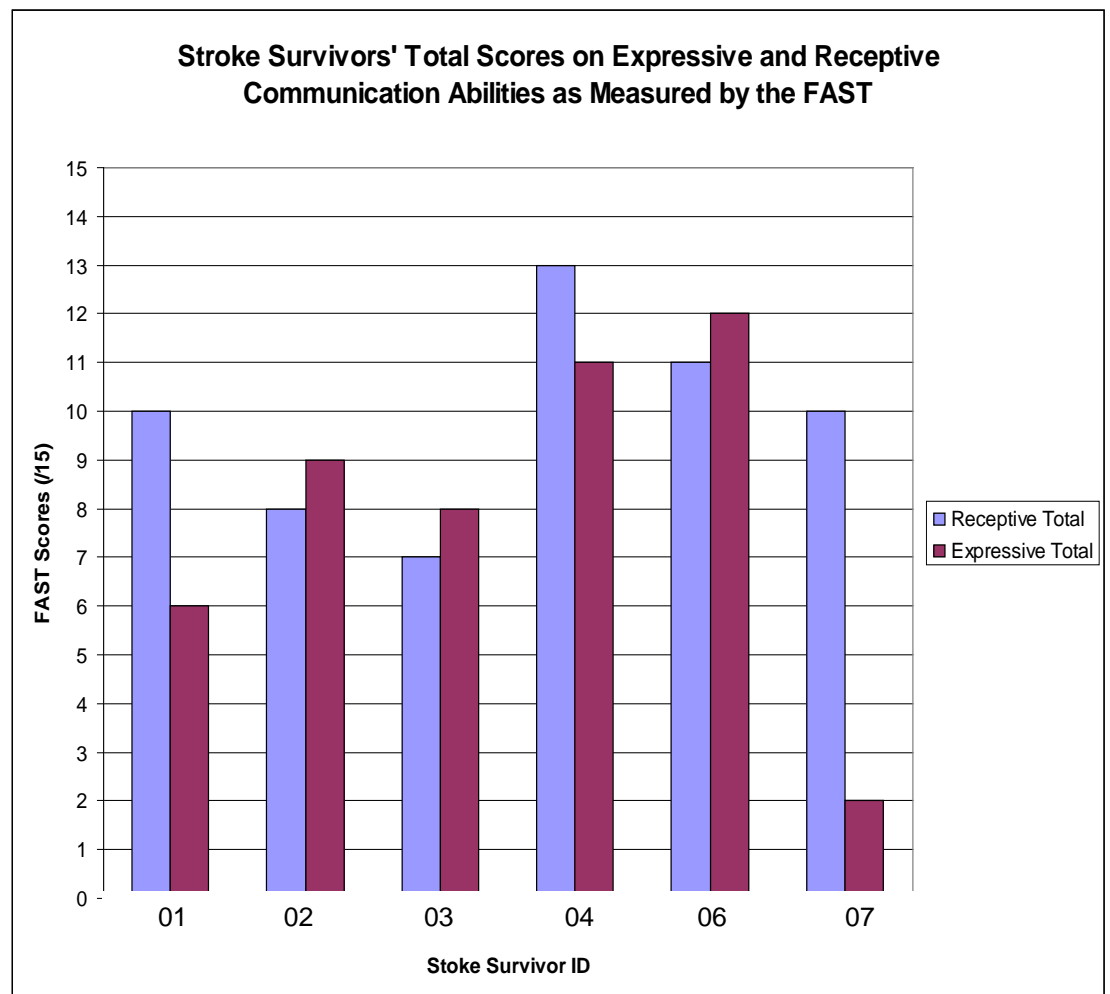


Figure 5. Figure 5 displays each participant's scores on the receptive and expressive domains of the FAST, providing an indication of their communication strengths and difficulties.

Data Analysis

The 49 Q set statements and data from the 11 Q sorts were entered into, and analysed using PQMethod computer software (Schmolck, 2014), using guidance from Watts and Stenner (2012).

Correlations Between Q Sorts. The nature and strength of relationships between Q sorts was determined using pair-wise correlations, indicating the degree of agreement in participants' ranking of statements (Kline, 1994). Table 5 shows the correlation matrix of pair-wise correlation coefficients.

Table 5

Correlation Matrix

	SS 01	S 01	SS 02	S 02	SS 03	S 03	SS 04	SS 06	S 06	SS 07	S 07
SS 01	0.10	<u>0.50</u>	0.46	0.17	0.21	0.23	0.8	-0.2	0.10	0.45	0.28
S 01		0.10	0.34	0.27	0.28	0.49	0.32	0.5	0.29	0.47	0.48
SS 02			0.10	<u>0.35</u>	0.25	0.31	0.6	0.9	0.25	0.54	0.35
S 02				0.10	0.37	0.23	0.23	0.32	0.53	0.15	0.56
SS 03					0.10	<u>0.50</u>	0.11	0.36	0.23	0.30	0.44
S 03						0.10	0.26	0.34	0.41	0.37	0.53
SS 04							0.10	-0.6	0.15	0.1	0.20
SS 06								0.10	<u>0.63</u>	0.33	0.43
S 06									0.10	0.40	0.62
SS 07										0.10	<u>0.48</u>
S 07											0.10

Note. The correlation coefficients between the stroke survivors' (SS) and spouses' (S) Q sorts. Significant correlations are emboldened ($r \geq 0.37$, $p < 0.01$, Brown, 1980; Watts and Stenner, 2012). Correlations between the stroke survivors and respective spouses are underlined.

Table 5 shows that each participants' Q sort correlated with at least two other participants, apart from that of stroke survivor 04, which did not correlate with any other Q sort, suggesting that their views were different to the other participants'. Correlations between stroke survivors and their respective spouses were significant ($r = \geq 0.37$, $p < 0.01$), positive and strong ($r = \geq 0.5$, Cohen, 1988), with the exception of stroke survivor and spouse 02, which was positive and of medium strength, but insignificant ($r = 0.35$), and stroke survivor 04, as their spouse did not complete a Q sort. Spouses can therefore reliably identify what their partners with stroke and aphasia deem as important to achieve a good quality of life.

Factor Analysis. Groups of inter-correlations within the data (factors) were identified, thus highlighting similarities in the participants' responses (Coolican, 2009). Q sorts showing commonalities were grouped into the same factor.

Principal Component Analysis (PCA) was used to explore the potential number of factors present in the data. A model that explains the largest amount of variance, with the fewest number of factors is desired (Pallant, 2010). Eleven components were initially detected. PCA produced the eigenvalues for each possible component, displayed in Table 6.

Table 6

Results of PCA.

The eigenvalues for the eleven possible components.

Components	Eigenvalue
1	4.2706
2	1.5841
3	1.1944
4	0.9036
5	0.7853
6	0.5782
7	0.4923
8	0.4201
9	0.3307
10	0.2385
11	0.2023

Kaiser Guttman criterion (Guttman, 1954, Kaiser, 1970, 1960) would suggest using a three factor model, as the eigenvalues of factors one to three are above one. However, when Centroid Factor Analysis was carried out with three factors, no Q sorts significantly loaded onto the third factor. Table 6 shows that the eigenvalue for factor three was only marginally above 1 (1.19), whereas the eigenvalues for factor one (4.27) and factor two (1.58) were considerably larger than 1. Cattell's scree test (Catell, 1966) was employed as an alternative method to determine the appropriate number of factors. The scree plot (Figure 6) shows that the shape of the curve begins to flatten at factor three, thus indicating the suitability of a two factor model, which would be

supported by Watts and Stenner (2012) who propose that one factor should be extracted for every six Q sorts. As 11 Q Sorts were obtained, two factors seemed appropriate to investigate.

Figure 6. Scree plot of eigenvalues for potential factors after PCA

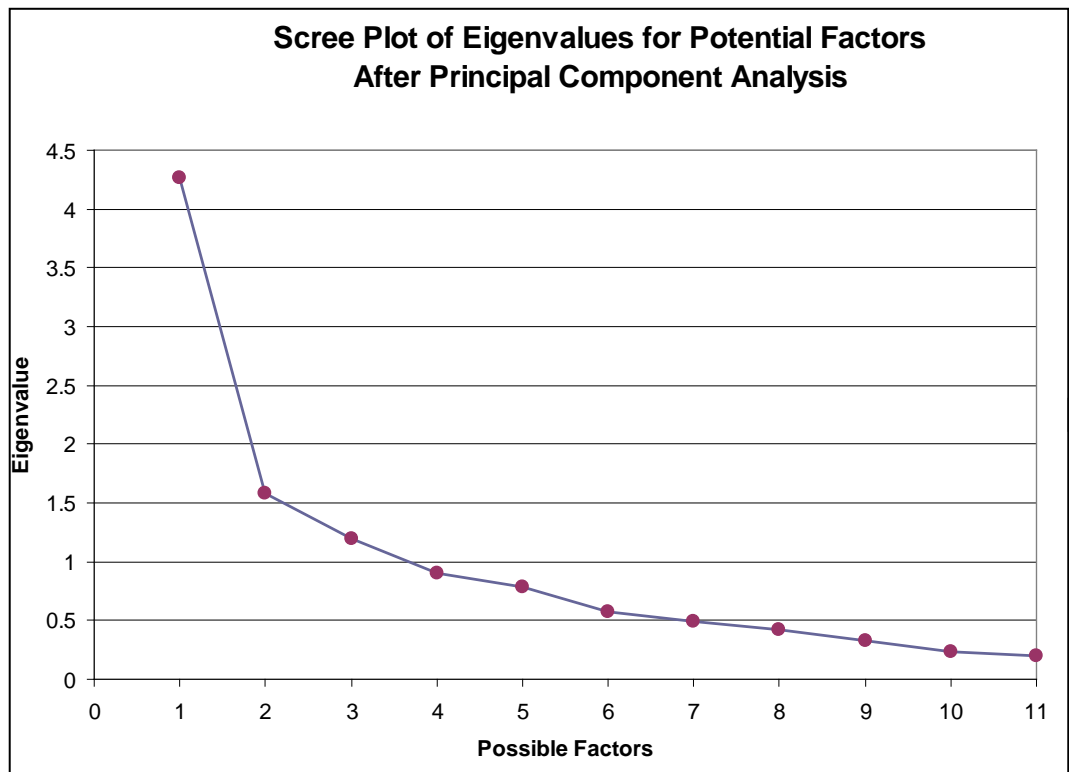


Figure 6. Cattell's Scree plot test (Cattell, 1966). Figure 6 shows the suitability of extracting two factors.

Centroid Factor Analysis was conducted, with the view to extract two factors, which were then subject to Varimax rotation. The resulting data, displayed in Table 7, shows the factor loadings of each Q sort on factor one and factor two, the factor eigenvalues and the percentage of variance each factor explained.

Table 7

Q sort factor loadings on factor 1 and 2.

Q Sort Participant	Factor 1	Factor 2
SS 01	-0.0118	0.6935X
S 01	0.3493	0.5720X
SS 02	0.1953	0.6033X
S02	0.6002X	0.1660
SS 03	0.5054X	0.2430
S 03	0.5607X	0.3726
SS 04	0.1984	0.1227
SS 06	0.5979X	-0.0541
S 06	0.7174X	0.1598
SS 07	0.2641	0.6776X
S 07	0.7492X	0.3790
Eigenvalue	2.64	2.09
Percentage of Variance Explained	24	19

Note. Table 7 shows the factor loadings of each stroke survivors' (SS) and spouses' (S) Q sort upon factors one and two. A significant factor loading, was ≥ 0.37 ($p < 0.01$) using Brown's (1980) calculations. Q sorts with significant factor loadings are identified with an 'X'. The factors' eigenvalues and the percentage of variance explained are shown.

Table 7 shows that factor one consisted of the Q sorts from spouse 02, stroke survivor and spouse 03, stroke survivor and spouse 06 and spouse 07. Factor two consisted of the Q sorts from stroke survivor and spouse 01, stroke survivor 02 and stroke survivor 07. The Q sort produced by stroke survivor 04 did not significantly load onto either factor. There were no confounding Q sorts loading significantly onto both factors. This two factor model explains 43% of the variance (24% by factor 1 and 19% by factor 2) A successful model explains at least 35-40% of the variance (Watts and Stenner, 2012), indicating that this two factor model is sufficient. The Kaiser Guttman Criterion also confirms that that this model is satisfactory, as the eigenvalues for each factor exceed one.

Factor arrays were produced for both factors one and two (Appendix J). A factor array is a single Q sort, depicting the overall ranking of statements, representing the general viewpoint of a factor,

based on the Q sorts of the participants that significantly loaded onto the factor (Watts and Stenner, 2012).

Discussion

Factor array content and participant demographics were explored, in light of psychological theory and an interpretation of the factor viewpoints and meanings was developed.

Factor One: 'Returning to the Pre-Stroke Self.' Q sorts from six participants (spouse 02, stroke survivor and spouse 03, stroke survivor and spouse 06 and spouse 07) loaded significantly onto this factor, resulting in the factor array and ranking of statements depicted in Appendix J. Participants were four spouses (two male, two female) and two stroke survivors (one male, one female). Ages ranged from 50 to 73 years, with five participants of working age (≤ 65 years old). One spouse was working, one retired, one was a carer and one was unemployed, in a caring role. The stroke survivors were not working, but aimed to return to employment.

This factor indicated a value in physical recovery from the stroke, regaining independence, and reconnecting with previous roles, responsibilities and routine. The importance of independence was implied by a number of highly rated statements: completing activities of self care by themselves (+4), making their own decisions (+4), doing general activities by themselves (+3) and getting around independently (+3). The value in physical recovery was suggested by the statements: being able to think clearly, to concentrate and remember (+5) and having a body that functions well (+3). A positive outlook (+4), and hope for an improved future, may provide the motivation required for physical recovery. Other salient features seemed to be related to regaining pre-stroke roles and responsibilities (+2), including returning to work (0), which would provide a sense of meaning and purpose in life (+3). This interpretation was supported by demographics of participants contributing to this factor, as they were generally of working age, and verbal feedback from the stroke survivors confirming that employment was important.

The content of factor one is supported by previous quality of life, post-stroke and aphasia literature. Completing activities has been found to contribute to improved quality of life, by doing as much as possible (Cruice *et al* 2010; Hilari *et al.*, 2003) and completing meaningful activities, including working (Cruice *et al.*, 2010; Dalemans *et al.*, 2010; Grohn *et al.*, 2012; Mumby and Whitworth, 2013; Parr *et al.*, 1997). Partaking in activities indicates a level of independence, which is valued (Armstrong *et al.*, 2012; Cruice *et al.*, 2010, Grohn *et al.*, 2012) and enables the individual to return to their pre-stroke roles (Armstrong *et al.*, 2012). The ability to perform ADLs, physical recovery from stroke symptoms, body functioning and good health are also necessities for a good quality of life (Cruice *et al.*, 2010). A positive outlook was found to contribute to a good quality of life, which Grohn *et al.* (2012) proposed incorporated 'optimism, hope, determination and gratitude' (p. 396).

Factor Two: 'Life Beyond Stroke, What's Important Now?' Q sorts from four participants (stroke survivor and spouse 01, stroke survivor 02 and stroke survivor 07) loaded significantly onto this factor, resulting in the factor array and ranking of statements depicted in Appendix J. The participants were one spouse (female) and three stroke survivors (two male, one female). Ages ranged from 57 to 71 years. One participant was of working age; a stroke survivor, four months post-stroke, currently unable to work. Their recovery priority was physical rather than vocational. The remaining three participants were retired.

The meaning of this factor was that of acceptance of changes (+2) post-stroke, and the necessity to adapt (adapting hobbies; 0, making adaptations to the home; +2). There was an appreciation of health care support (+4) and gradual improvements (doing things gradually and being determined; +2) in their basic self care (+3). A personal understanding of aphasia (+4) and others knowing about the condition (0) was valued. Salient features in achieving a good quality of life were those beyond stroke recovery, including spending time with family (+4), living in their own home (+5), and seeing old friends (0). Communication was important; being able to communicate with others

(+3), to express difficult feelings (+3) and sharing a sense of humour (+3). Participants contributing to this factor were generally older adults, and retired, reflected in the relative unimportance of work or education (-3).

Factor two was supported by findings of previous literature. Spending time with friends and family has been found to be imperative to attaining a good quality of life (Cruice *et al.*, 2010). Other people have three main roles: provision of practical and emotional support (Armstrong *et al.*, 2012; Brown *et al.*, 2013; Grohn *et al.* 2012), company, and to complete activities with (Brown *et al.*, 2013; Niemi and Johansson, 2013). High levels of social support have been associated with a higher quality of life (Hilari *et al.*, 2003), although the amount of time spent with family is critical; if this is increased post-stroke, it can imply increased dependence, which can reduce quality of life (Hilari and Northcott, 2006). The necessity to understand, and to aid others' understanding of aphasia is acknowledged by previous research (Cruice *et al.*, 2010; Hilari *et al.* 2003; Mumby and Whitworth, 2013), which contribute to an adjustment/ adaptation process. Doing things gradually and adapting an approach to activities has been found to be important (Niemi and Johansson, 2013) as has the need for hope for further recovery (Cruice *et al.*, 2010; Mumby and Whitworth, 2013) which supports the current finding that healthcare provision was appreciated. Lastly, an importance of living in one's own home, and making necessary amendments, has also been found to be important to having a good quality of life (Cruice *et al.*, 2010).

Insignificant Q Sort Factor Loadings. The Q sort of stroke survivor 04 did not load significantly onto either factor, suggesting that his beliefs were different to those of other participants. He was a carer for his spouse, rather than cared-for, which may explain the differences in priorities. The Princess Royal Trust for Carers (2011) summarised that approximately 16% of people aged 65 to 74 years old, and 13% of those aged 75 years and over are informal carers for a friend or family member, with two thirds of older carers have long-term health conditions themselves. It may be that stroke survivor 04 represented

the beliefs of older carers experiencing their own health difficulties. Returning to a pre-stroke self seemed important, (being independent; +5), with a strong value of external support; attending stroke groups (+4), having the help needed to recover (+4), and exercise (+4) (on prescription). Being a carer, rather than cared-for, he may have been more reliant upon external support for recovery. Practising communication activities (+5) was ranked highly, possibly because his SALT input had recently finished, so continued improvement was his responsibility. The emphasis on recovery may reflect the need to regain the ability to care for his spouse; 80.7% of older adult carers have concerns about the future wellbeing of the person they care for, should they be unable to support them (The Princess Royal Trust for Carers, 2011). A close and intimate relationship with my spouse was ranked at +3, compared to +5, akin to other participants, which may be suggestive of the differing qualities of their relationship. He was retired, so returning to work or education (-4) was less of a priority, and he valued religion (spirituality; +1), which was different to other participants. Elements that were most unimportant, were things that he had not done, such as adapting his home (-4) and hobbies (-5) and seeing old friends (-5).

Comparison of Factors. In both factors, a close and intimate relationship with their partner was ranked most highly (+5), suggesting that this was a fundamental feature, regardless of other aspects influencing quality of life. This could also reflect a sampling bias as the inclusion criteria required the stroke survivor to have a spouse. A partner willing to support them with research may be indicative of a strong and supportive relationship, represented by the highly ranking 'close and intimate relationship'. Meaningful relationships have been found to contribute to a good quality of life (Cruice *et al.*, 2010), although some studies have not found marital status to be associated with quality of life (Hilari *et al.*, 2003) or have found those without a spouse or children to have a higher quality of life (Hilari and Northcott, 2006).

Statements that were most unimportant to factor one were similar for factor two, including attending stroke groups, day centres and support

groups (factor one; -5, factor two; -4), volunteering (factor one; -5, factor two; -4), having a pet (factor one; -4, factor two; -5), spirituality (factor one; -4, factor two; -5) and making new friends (factor one; -3, factor two; -4). Based on participant feedback, these items were not a priority prior to the stroke and remained unimportant, e.g. 'spirituality,' or were aspects that they had not contemplated, such as attending stroke groups or volunteering. Conversely, previous research has found that attending stroke groups, day centres and support groups can be a useful source of support and encouragement (Brown *et al.*, 2013 and Grohn *et al.*, 2012), and that volunteering has been of value to some aphasic stroke survivors (Cruice *et al.*, 2010). Stenner *et al.* (2003) found that faith was associated with quality of life, which was presently only important for one stroke survivor. Having a pet was generally not deemed advantageous, although two stroke survivors mentioned the desire to have a dog, but impracticalities post-stroke prevented this. Previous research has found that pets can aid recovery (Adair, Ewing and Pfalzgra, 1990), for example, through animal assisted therapy (Macauley, 2006), but the current findings challenge this notion. Seeing old friends was rated higher in factor two, but was not ranked higher than 0 in either factor. Other findings suggest that aphasic stroke survivors lose friends (Hilari and Northcott, 2006) due to limited opportunities for socialising, resulting from increased physical and communication difficulties and dependency on others (Brown *et al.*, 2013), which may be reflected by the low ranking of this statement. Lastly, communication was more important for factor two, but did feature in factor one (+2). Neither factors rated communicating with others higher than +3, and practising communication activities was not ranked higher than +1, indicating that other areas of recovery were a greater priority, akin to Armstrong *et al.* (2012) and Cranfill and Wright (2010).

Psychological Theory. The differences between the two factors appear to relate to life cycles. The younger generation prioritised physical recovery, independence and regaining pre-stroke roles and responsibilities (factor one), and the older generation placed more value

on adapting to their new situation and understanding aphasia, alongside an appreciation of support and recovery, friends and family and their home (factor 2). Erikson's (1968) psychosocial stages of development model suggests that the individual lifecycle consists of stages, each presenting a 'social dilemma' to be resolved, to achieve a good quality of life (Carr, 2000). The differences in the priorities for quality of life identified by factor one and two can be considered in relation to this theory. Participants expressing the viewpoint held by factor one were primarily of working age, and therefore fall into the 'Generativity versus Stagnation' stage (aged 40 to 65 years). Successful completion of this stage requires tailoring ones' work and home environment to enhance productivity and enable societal contribution, through raising children within a settled relationship, attaining a satisfactory vocation, or developing one's creativity. This suggests that physical recovery, returning to the pre-stroke self and regaining employment would be essential to this age group of stroke survivors. If this stage is not successfully completed, individuals may become stressed, depressed or cynical or alternatively, greedy or narcissistic (Carr, 2000; McLeod, 2008). Participants contributing to factor two were primarily older adults, entering Erikson's 'Ego Integrity versus Despair stage,' which requires individuals to contemplate their life events, developing a life story, incorporating both their achievements and failures. A challenging process, but if achieved, virtues of integrity and wisdom are established, and one can feel at peace with the prospect of death. If unable to resolve this dilemma, for example, if life goals were not met, the consequence is despair and a fear of death (Carr, 2000, McLeod, 2008). The viewpoint of factor two, of those aged 65 years and above, are in accordance with Erikson's model, such that productivity and associated activities did not seem to be a priority; there is a greater emphasis on the need for acceptance of adversities, such as the stroke, and focussing on other important achievements, including family, friends and their home, to attain a good quality of life.

It is also possible however, that factors one and two reflect stages of stroke recovery. Evidence denotes four stages of adjustment

(Holbrook, 1982; Kirkevold, 2002). The first stage encompasses feelings of shock and confusion, a possible difficulty in accepting support from health professionals, regarding the stroke as an isolated life event. A rehabilitation phase proceeds, in which stroke survivors work hard and focus upon physical recovery and progress. Denial of the permanency of stroke symptoms may exist, in addition to grieving reactions. The third phase concerns the development of emotional responses such as anger, frustration, despair, depression, particularly on discharge and realisation that complete recovery may be unlikely. The last stage is one of acceptance and adjustment to a new sense of self, incorporating stroke-induced changes and managing the incongruities between expected and actual stroke recovery (Ch'Ng, French, Mclean, 2008; Lincoln, Kneebone, Macniven and Morris (2012).

Factor one could illustrate the viewpoint of participants in the second stage of stroke recovery; focussing on rehabilitation and a determination to achieve full physical recovery, returning pre-stroke roles and responsibilities. Factor two may represent the viewpoint of participants entering the fourth stage of recovery and an acceptance of the new circumstances and an ability to adapt their life to manage the residual symptoms. An acknowledgement that expressing difficult feelings, such as worry, sadness and frustration is helpful, may indicate that they have passed through the emotional third stage, and are managing the sentiments of stage four.

Summary

Q methodology was used to ascertain what factors were important to achieving a good quality of life, post-stroke and aphasia, from the stroke survivors' perspective and proxy reports from their spouses. Q sorts were completed with six stroke survivors and five spouses and two overarching factors were identified. Factor one, returning to the pre-stroke self, reflected the views of the younger participants, and factor two, life beyond stroke, what's important now?' was more applicable to the older, retired participants. These two factors could be representative of Erikson's (1968) psychosocial stages of

development model, or models of stroke recovery (Holbrook, 1982; Kirkevold, 2002). Stroke survivor 04 did not share the same beliefs as the other participants, which could reflect his caring role. The Q sorts produced by each couple were largely and significantly correlated, with the exception of couple 02. These results add to the findings of the mixed evidence base regarding the validity of proxy reports. The couples in the present sample had known each other for a minimum of 18 years, and all co-habited, which is in support of Hilari *et al.*'s (2007) conclusion that caregivers with frequent contact with the stroke survivor are able to act as suitable proxies.

Limitations

Sample Size. Eleven participants, six aphasic stroke survivors and five spouses, completed the Q sort task. The relatively small sample size, although appropriate for Q methodology (Watts and Stenner, 2012), highlights issues of generalisability of the findings. Aphasic stroke survivors are a hard to reach population, thus any research aiming to capture and share their viewpoints is valuable.

Sample Bias. The stroke survivors experienced both expressive (mild to severe) and receptive (mild to moderate) aphasia. However, aphasia was assessed using the FAST, which is not a comprehensive communication assessment. This was appropriate for the level of information required for the study, but not to confirm the exact nature of aphasia. Those experiencing severe receptive aphasia were not included in the study, due to the exclusion criteria of attaining a score of $\geq 7/15$ on the FAST receptive domains to partake. This cut-off was implemented to ensure that participants understood the requirements of the Q sort task. All participants opting into the study reached this score. This could reflect a sample bias, as SALTs may have only introduced the study to individuals who were certain to score appropriately, avoiding unnecessary distress.

Inclusion criteria stipulated that stroke survivors had a spouse willing to take part. Considering that stroke predominantly occurs in people aged 65+ (Stroke Association, n.d.) and that only 56.8% of older

adults cohabit as a couple (Office for National Statistics, 2013) the current sample may not be truly representative of this population and therefore issues of generalisability of findings are acknowledged. SALTs reported difficulties in identifying stroke survivors that met this study criteria and it was hypothesised that this could be due to common age-related experiences, such as being widowed, or spouses having significant health difficulties. Consequently, there may be a bias in the ranking of the Q set statements. The highly ranked statement of 'having a close and intimate relationship' might be indicative of care and support and closeness from their spouses, which other stroke survivors may not experience.

Lastly, all participants had received SALT input, and most had additional forms of rehabilitation. Their Q sorts may not be representative of people who received limited rehabilitation support or those who had finished their rehabilitation and were further along in their recovery.

Participant Comprehension. Considerable efforts were made to ensure that the stroke survivors understood the Q sort task. However, it is possible that participants used the task to indicate what they have in their lives at present, rather than what would be important to achieve a good quality of life, which may affect the validity of the results.

Confounding Variables. Data about possible confounding variables, such as stroke and aphasia type and severity was not easily accessible, and therefore the impact of such factors upon quality of life is unknown.

Clinical Relevance

The outcomes of the study have a number of implications. Firstly, that people with aphasia can be included in research. Secondly, it is necessary to understand what is important to achieve a good quality of life post stroke and aphasia, so that rehabilitation services can provide suitable recovery support. Thirdly, that Q methodology, when adapted to accommodate communication difficulties, can be used as a form of

communication aid, providing people with aphasia with a means of expressing their beliefs. Consequently, this method could be a useful tool to be used to support psychological therapy. Emotional difficulties can be present after stroke including depression, anxiety, frustration, apathy and adjustment problems, thus individuals may benefit from psychological intervention (Lincoln *et al.*, 2012). Talking therapy is often inaccessible to people with aphasia (Thomas *et al.*, 2012), but the Q sort technique may help to overcome any language barriers. Fourthly, the results suggest that spouses can reliably represent their aphasic partners' opinions regarding factors enhancing their quality of life, at times when it may be difficult to gather information from the aphasic stroke survivor. It may be useful to include spouses in therapeutic assessments and interventions. Fifthly, the findings support the notion that the factors that are important to attaining a good quality of life may vary, depending on the age and therefore, life stage of the stroke survivor, but also with regards to the stage of stroke recovery they face. When providing psychological interventions, this understanding is paramount in providing appropriate support. Lastly, a sense of individualising any rehabilitation support, when aiding stroke survivors to achieve a good quality of life was apparent, as not all participants shared the viewpoints of factors one and two.

Conclusion

The Q sort technique was used successfully with aphasic stroke survivors and their spouses to determine the factors that are important to achieve a good quality of life. Further research would be beneficial to address the sampling biases discussed. It is hoped that the present study highlights aspects to consider when working therapeutically with aphasic stroke survivors, thus adding to the knowledge regarding appropriate rehabilitation support.

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Appendices








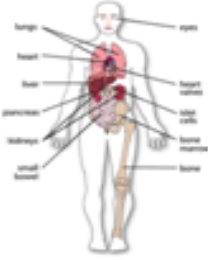


Appendix A. Ethical Approvals

Appendix A1. Ethical Approvals from the study sponsor,
Staffordshire University.

Appendix A2. Ethical Approvals from NHS East of Scotland Research
Ethics Service

Appendix B. R&D Approvals from Nottinghamshire County Health Partnerships and Nottingham City Care.

Appendix C. The Q Set

<p>Being able to communicate with others</p> 	<p>Understanding what aphasia is</p> 
<p>Using communication strategies (Gestures, pointing, facial expressions)</p> 	<p>Other people helping me to communicate (Taking time, listening, guessing what I'm saying)</p> 
<p>Practising communication activities - being proactive (Telephone, reading, writing letters, T.V. using the computer)</p> 	<p>Telling other people about aphasia - raising awareness</p> 
<p>Managing health problems</p> 	<p>My body functioning well</p> 
<p>Having energy</p> 	<p>Being able to think clearly - concentrate and remember</p> 

Appendix C. The Q Set

<p>Exercise</p> 	<p>Doing old hobbies</p> 
<p>Adapting hobbies</p> 	<p>Doing new hobbies</p> 
<p>Working or education</p> 	<p>Volunteering</p> 
<p>Keeping busy</p> 	<p>Doing household activities (cooking, cleaning)</p> 
<p>Doing my self care (washing, dressing)</p> 	<p>Relaxation</p> 

Appendix C. The Q Set

<p>Sense of humour – laughing</p> 	<p>Being free of difficult feelings (Sadness, worrying, frustration, embarrassment)</p> 
<p>Appreciating and enjoying life</p> 	<p>Doing things gradually, being determined</p> 
<p>Expressing difficult feelings (Sadness, worrying, frustration)</p> 	<p>Focussing on my progress/recovery</p> 
<p>Accepting that things have changed</p> 	<p>Practical support from others (friends, family, partner, neighbours)</p> 
<p>Emotional support from others (friends, family, partner, neighbours)</p> 	<p>Seeing old friends</p> 

Appendix C. The Q Set

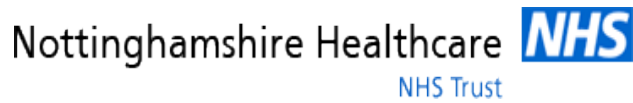
<p>Making new friends</p> 	<p>Spending time with family</p> 
<p>Having a pet</p> 	<p>Meeting other people with communication problems</p> 
<p>Having a close and intimate relationship with my partner</p> 	<p>Developing a new identity or sense of self</p> 
<p>Adapting my home to meet my needs</p> 	<p>Making my own decisions</p> 
<p>Doing activities by myself</p> 	<p>Getting around independently</p> 

Appendix C. The Q Set

<p>Spirituality</p> 	<p>Keeping the same roles and responsibilities</p> 
<p>Having a purpose and meaning in life</p> 	<p>Having goals</p> 
<p>Having a positive outlook</p> 	<p>Living in my own home</p> 
<p>Attending stroke clubs, day centres, support groups</p> 	<p>Having the help I needed to recover (Speech and Language therapy, Physiotherapy, Occupational therapy, Doctors, home support, psychological therapy)</p> 
<p>Services understanding aphasia, and making adaptations. (Including aphasia friendly information)</p> 	

Appendix D. Invitation Pack

Appendix D1. Cover Letter



Principal Investigator
Address

Dear

I would like to **invite you to take part** in a **research study**.

It is about the **quality of life after stroke** for people who have **communication difficulties**.

We are looking for **stroke survivors with communication problems and their spouse** to take part.

I have included an **information sheet**, an **opt-in slip** and a **pre-paid envelope**.

If you are interested in **taking part**, or finding out **more information**, please **return the opt-in slip** using the **envelope provided**.

If you have any **questions**, you can contact me on

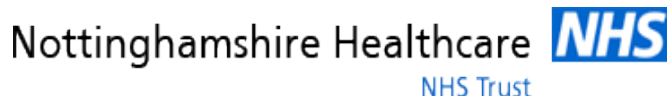
Phone:

Email:

Kind regards

Principal Investigator

Appendix D2. Participant Information Sheet



Participant Information Sheet

**Quality of Life After Stroke and Aphasia:
Stroke Survivors' and Spouses' Perspectives**

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

Please contact me if there is anything that is not clear of if you would like more information. Take time to decide whether or not you wish to take part

What is the purpose of the study?

The study is looking at the impact of stroke and subsequent communication difficulties (aphasia) on the quality of life of the stroke survivor, from the perspectives of the stroke survivor themselves and also their spouse.

The study will hopefully highlight areas that stroke rehabilitation services need to address when supporting aphasic stroke survivors, to help improve their quality of life. It will also hopefully add to the current literature about the reliability of using spouses' ratings to assess the stroke survivor's quality of life.

The study is a Clinical Psychology Doctoral thesis.

Why have I been invited?

You have been invited because we are interested in people with communication difficulties following a stroke and their spouses. In total, 20 people with communication difficulties and their spouses will be recruited to take part in the study.

Do I have to take part?

It is up to you to decide. The study is described in this information sheet and I am happy to visit you at home to explain the study to you and to answer any questions you may have. Taking part is voluntary. If you do choose to take part, you will be asked to sign a consent form to show that you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

Appendix D2. Participant Information Sheet

What will happen to me if I take part?

Once consent forms have been signed by the stroke survivor and their spouse, the stroke survivor will complete a communication assessment to determine whether the study is suitable for them. If so, further assessments will be completed with both of you, to gather general information about yourselves and the stroke, and to assess the stroke survivor's mood, and ability to carry out day-to-day activities. This will take approximately 45 minutes. A second visit will then be arranged in which a card sorting task will be carried out with both the stroke survivor and the spouse, separately. This will involve placing a number of cards depicting various beliefs about the quality of life, and factors impacting this, in order of personal importance. This will take up to an hour and a half.

If you decide that you would like to take part, or to discuss the study further, then please complete the opt-in slip included. You may then be contacted to arrange an initial home visit with the researcher to discuss the next steps. It may not be necessary for everyone who completes an opt-in form to take part - you will be informed of this by letter if this is the case.

Expenses and payments

You will not receive any payments for taking part in the study. The researcher will visit you at home to complete the assessments and the card sorting task, so this will not be an expense to you. Any information that needs to be sent by post will be paid for by the study.

What are the possible disadvantages and risks of taking part?

There is a potential risk that you may become distressed when taking part in this study, as you will both be asked to consider the impact of the stroke and subsequent communication difficulties on the stroke survivor's quality of life. A list of organisations that you can contact for further support post stroke, including the Stroke Association, will be provided to you by the researcher.

What are the possible benefits of taking part?

We cannot promise that the study will help you, but the information we gather will hopefully help to improve the rehabilitation treatment of people with aphasia following stroke and add to the current literature about the reliability of using the spouses' ratings to assess the stroke survivor's quality of life.

What if there is a problem?

If you wish to make a complaint about any aspect regarding the way you have been treated during this study, there are a number of means to do so. You are welcome to contact the Principal Investigator, or alternatively either of the project supervisors, who will do their best to answer your questions and support you with your concerns (see contact

Appendix D2. Participant Information Sheet

details below). If you remain unhappy and would like to make a more formal complaint, then you can follow the NHS complaints procedure by contacting the Patient Advice and Liaison Service on 01623 673849 (Nottinghamshire County participants) or 0115 883 9654 (Nottingham

City participants), or follow the Staffordshire University complaints procedure, details of which can be accessed from:
[http://www.staffs.ac.uk/assets/complaints%20 procedure tcm44-26818.pdf](http://www.staffs.ac.uk/assets/complaints%20procedure_tcm44-26818.pdf).

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against Nottinghamshire Healthcare NHS Trust or Staffordshire University, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Procedures for handling, processing, storing and destroying your data will conform to the Data Protection Act (1998) guidance.

Data will be collected from yourselves through the assessments and the card sorting task. Whilst the research is being conducted, the data will be stored in a locked cupboard at the University of Nottingham. Data that identifies you will be kept separately from the outcomes of the assessments and the card sorting task. The Principal Investigators and the project supervisors will be the only people to view your data. The data will solely be used for the purposes of this study.

If at any point the researcher becomes concerned about your safety or the safety of others, we will ask for your permission to contact your G.P.

On completion of the study, the data will be completely anonymised and stored at Staffordshire University for 10 years, when it is then securely disposed of.

What will happen if I don't want to carry on with the study?

You have the right to withdraw from the study at any time, without giving a reason. We just ask that you inform the researcher that this is the case. We will retain data collected up until your withdrawal.

What will happen to the results of the research study?

The study is part of the Principal Investigator's Clinical Psychology doctoral thesis. You will not be identified in any report/publication. If you wish to receive a summary of the results, please inform the researcher.

Appendix D2. Participant Information Sheet

Who is organising and funding the research?

The sponsor of the study is Staffordshire University.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given

Appendix 4b: Participant Information Sheet

favourable opinion by The East of Scotland Research Ethics Committee REC 1.

The East of Scotland Research Ethics Committee REC 1, has responsibility for scrutinising all proposals for medical research on humans, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from the Staffordshire University and Nottinghamshire Healthcare NHS Trust, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

Further Information and Contact Details

If you have any further queries about the study, then please do not hesitate to contact the Principal Investigator or the project supervisors using the contact details below.

Principal Investigator:

Email:

Project Supervisor:

Email:

Telephone:

Project Supervisor:


Email:

Telephone:

Thank you for reading this information sheet.

If you would like to take part in the study, then please complete the opt-in slip and return in the pre-paid envelope.

Appendix D3. Opt-In slip

Nottinghamshire Healthcare 
NHS Trust



Opt- In Slip

Name:

Address:

Telephone Number:

(Please tick box)

I would like to:

☐

Take part in the study

☐

Find out more about the study

Please contact me to arrange a home visit by:

☐

Telephone

☐


Letter

Date:

Signed:

Please return in the prepaid envelope, thank you.

Appendix E. Aphasia Friendly Information sheet, adapted from those used by Thomas, Walker, Macniven, Haworth, and Lincoln (2013).

Nottinghamshire Healthcare 
NHS Trust



Quality of Life after Stroke and Aphasia Stroke Survivors' and Spouses' Perspectives

Emma Ford

Trainee Clinical Psychologist

Research about the **quality of life** after experiencing
a **stroke** and **communication problems**

Approved by the
East of Scotland Research Ethics Committee
REC 1

Appendix E. Aphasia Friendly Information sheet

Quality of Life After Stroke and Aphasia

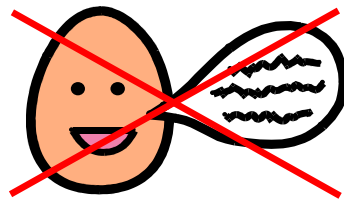
Appendix E. Aphasia Friendly Information sheet

Can you help our research?

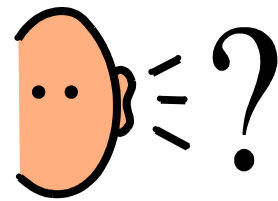


Appendix E. Aphasia Friendly Information sheet

After a **stroke**, some people find it **hard** to **communicate**.



Talking



Understanding



Reading



Writing

Appendix E. Aphasia Friendly Information sheet

What is the study about?



The **quality of life** of **stroke** survivors with **communication problems**.

The **Stroke survivors'** and their **spouses'** views

Appendix E. Aphasia Friendly Information sheet

You can decide if you want to **take part**.

It is **your choice**.



Appendix E. Aphasia Friendly Information sheet

If you take part...



You can **stop** at **any time**.

You will not need to give a reason.

Appendix E. Aphasia Friendly Information sheet

You will **still receive** all your **normal care**.



Appendix E. Aphasia Friendly Information sheet

What will I have to do?

1. A communication assessment, to see if the study is suitable for you.

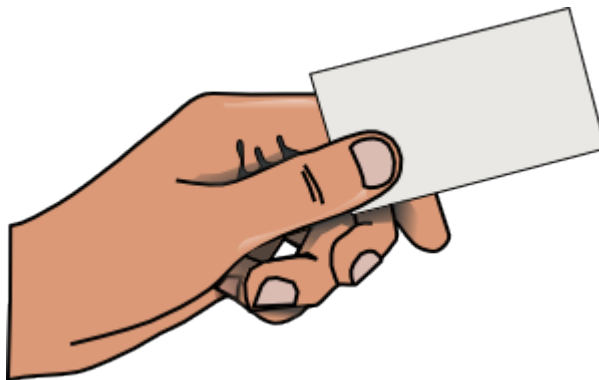
2. If suitable, some **questionnaires** will be done with you and your spouse, about:

- **Mood**
- **Activities**
- **General information**



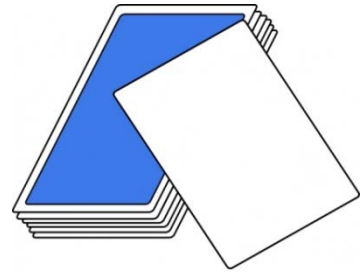
Appendix E. Aphasia Friendly Information sheet

3. You and your **spouse** will complete a **card sorting task**, individually, with my help.



This can be done at a time that is good for you.

Appendix E. Aphasia Friendly Information sheet



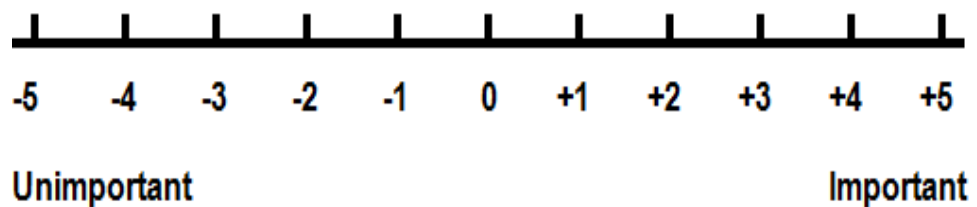
Card Sorting Task

We want to know **what is important** to you to have a **good quality of life since** having a **stroke** and **communication problems**.

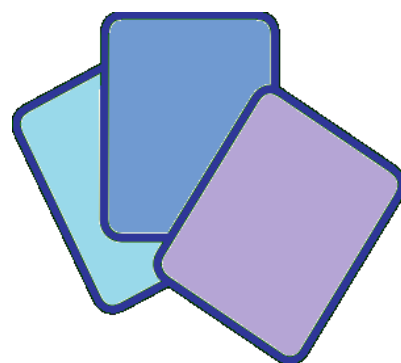
You will be **given some cards**. Each card will say something about the quality of life and things that might affect this.

Appendix E. Aphasia Friendly Information sheet

You will be asked to **put these cards in order**, depending on how **important** they are **to you**, to have a **good quality of life**.

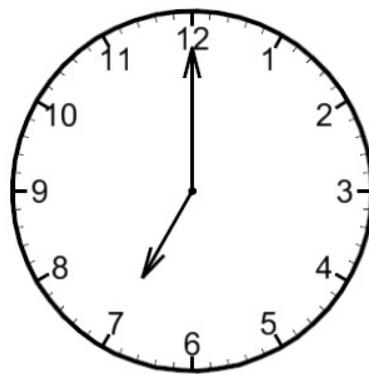


Your spouse will also be asked to do this task, separately.



Appendix E. Aphasia Friendly Information sheet

How long?



It could take up to **1 hour and 30 minutes** for **both** of you to **complete the task**.

Appendix E. Aphasia Friendly Information sheet



All of your information will be **confidential**.

~~**name**~~

Your name will **NOT** be used

Information will be kept in a **locked cupboard**.

Appendix E. Aphasia Friendly Information sheet

What are the benefits?

We will understand more about the quality of life after stroke and aphasia.

May improve services.

It may not benefit you directly.

What will happen to the research?



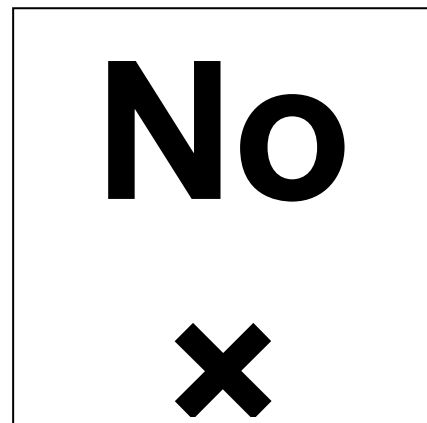
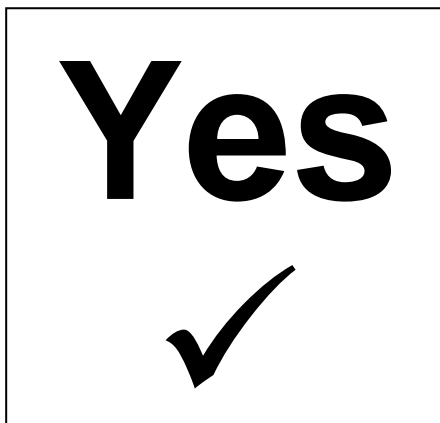
Emma is training to be a Clinical Psychologist.

*Results will be written up as a Doctoral **thesis.***

Please ask if you would like a **copy of the results**

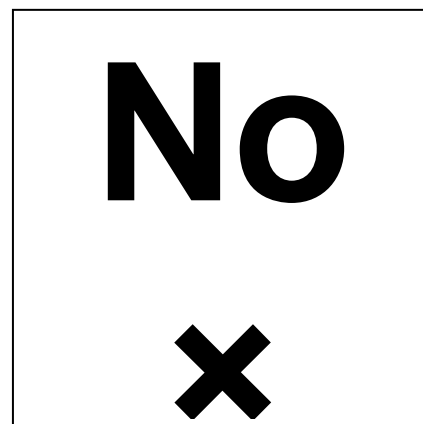
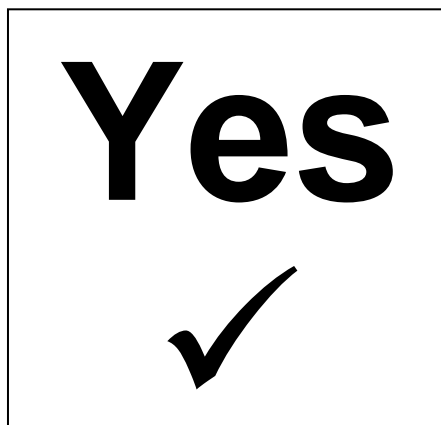
Appendix E. Aphasia Friendly Information sheet

Do you understand?



Appendix E. Aphasia Friendly Information sheet

Do you want to take part?



Appendix E. Aphasia Friendly Information sheet

Please sign our consent form.



Appendix E. Aphasia Friendly Information sheet

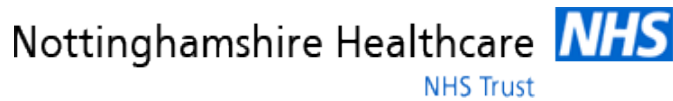
Thank you

If you have any **questions** please contact:

Emma Ford

(See information sheet for contact details)

Appendix F. Consent form



Consent Form

Title of Project: Quality of Life After Stroke and Aphasia: Stroke Survivors' and Spouses' Perspectives

Name of Researcher: Emma Ford

1. I confirm that I have read and understand the information sheet dated November 2013 (Version 3) and/or the aphasia friendly information sheet dated November 2013 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person
Signature
taking consent

Date

Appendix G. Questionnaires to assess communication ability, mood, daily activities and physical ability.

Appendix G1. Frenchay Aphasia Screening Test

Appendix G2. 'Sad' Visual Analogue Mood Scale
(VAMS; Stern, 1996)

Appendix G3. Stroke and Aphasia Depression Questionnaire
Hospital 10 (SADQ-H10; Lincoln, Sutcliffe and Unsworth, 2000)

Appendix G4. Bartel Index (Wade and Collin, 1988)

Appendix G5. Nottingham Extended Activities of Daily Living
(NEADL; Nouri and Lincoln, 1987)

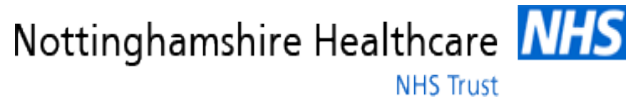
Appendix G5. Nottingham Extended Activities of Daily Living
(NEADL; Nouri and Lincoln, 1987)

Appendix H. Contacts for further support

Should you feel **distressed** after taking part in the research study, there are some **organisations** you can **contact** for **help**:

- Your **G.P.**
- **NHS Direct**
 - 0845 46 47
 - www.nhsdirect.nhs.uk/
- The **Samaritans**
 - 08457 90 90 90
 - jo@samaritans.org
 - <http://www.samaritans.org/how-we-can-help-you/contact-us>
- The **Stroke Association**
 - 0303 3033 100
 - info@stroke.org.uk
 - <http://www.stroke.org.uk/>

Appendix I. Participant Demographics Questionnaire



Demographic Questionnaire

Stroke Survivor

Name:

DOB:

Address:

Telephone:

Email:

G.P. Name and Address:

Ethnic Background:

Marital Status:

Employment Status (including last paid job):

Reported Communication Difficulties:

Stroke Details: *(Date, type, side of lesion, length of stay in hospital)*

Support and Treatment Received *(Past and Present)*:

Spouse

Name:

DOB:

Address:

Telephone:

Email:

G.P. Name and Address:

How Long they have Known Stroke Survivor (Years):

Appendix J. Factor Arrays

Factor Arrays

No.	Content	<u>Statement</u>	<u>Factor Arrays</u>	
			Factor One	Factor Two
1	Accepting that things have changed		0	2
2	Adapting hobbies		-2	0
3	Adapting my home to meet my needs		-4	2
4	Appreciating and enjoying life		1	-1
5	Attending stroke groups, day centres, support groups		-5	-4
6	Being able to communicate with others		2	3
7	Being able to think clearly – concentrate and remember		5	0
8	Being free of difficult feelings (sadness, worrying, frustration, embarrassment)		1	-1
9	Having a close and intimate relationship with my partner		5	5
10	Developing a new identity or sense of self		-1	-1
11	Doing activities by myself		3	-3
12	Doing household activities (cooking, cleaning)		-1	-2
13	Doing my self care (washing, dressing)		4	3
14	Doing new hobbies		-3	-3
15	Doing old hobbies		-2	-2
16	Doing things gradually, being determined		0	2
17	Emotional support from others (friends, family, partner, neighbours)		0	-1
18	Exercise		0	-1
19	Expressing difficult feelings (sadness, worrying, frustration)		-1	3
20	Focussing on my progress/recovery		1	1
21	Getting around independently		3	0
22	Having a pet		-4	-5
23	Having a positive outlook		4	2
24	Having a purpose and meaning in life		3	0
25	Having energy		2	-2
26	Having goals		1	0
27	Having the help I needed to recover (Speech and language therapy, Physiotherapy, Occupational Therapy, Doctors, home support, psychological therapy)		2	4
28	Keeping busy		1	0
29	Keeping the same roles and responsibilities		2	-1
30	Living in my own home		1	5
31	Making my own decisions		4	-1

Quality of Life After Stroke and Aphasia

32	Making new friends	-3	-4
33	Managing health problems	0	1
34	Meeting other people with communication problems	-3	-3
35	My body functioning well	3	0
36	Other people helping me to communicate (taking time, listening, guessing what I'm saying)	0	1
37	Practical support from others (friends, family, partner, neighbours)	0	1
38	Practising communication activities (telephone, reading, writing letters, T.V., using the computer)	0	1
39	Relaxation	-3	-2
40	Seeing old friends	-2	0
41	Sense of humour – laughing	-1	3
42	Services understanding aphasia and making adaptations (including aphasia friendly information)	-1	1
43	Spending time with family	2	4
44	Spirituality	-4	-5
45	Telling other people about aphasia – raising awareness	-2	0
46	Understanding what aphasia is	-1	4
47	Using communication strategies (gestures, pointing, facial expressions)	-2	2
48	Volunteering	-5	-4
49	Working or education	0	-3

Quality of Life After Stroke and Aphasia: Author's Reflections

The Health and Care Professions Council (HCPC), the statutory regulatory body with whom clinical psychologists are required to register, highlight the importance of partaking in reflective practice, as part of ones' continuing professional development, paramount to 'learning and development, maintenance of up-to-date skills and knowledge and ensuring safe, legal and effective practices' (HCPC, 2011, p.1). There are a number of models of reflection to assist professionals when engaging in this process (Finlay, 2008). A widely used model is that of Boud, Keogh and Walker (1985), comprising three stages: (a) returning to experience, which involves producing a detailed, non-judgmental account of the experience, including evoked emotions, (b) attending to feelings, both positive and negative, and processing the negative emotions to ensure that learning is not obstructed and (c) re-evaluating the experience, to which there are four sub-stages: association (combining thoughts and feelings), integration (developing a new perspective, belief or attitude), validation (determining whether the new views are consistent with other information or opinions) and appropriation (incorporating the ideas into the reflector's perspective) (Finlay, 2008; McAllister, Lincoln, McLeod and Maloney, 1997). This framework has been used as a guide to reflecting upon the experience of completing a clinical psychology doctoral thesis.

Returning to Experience

As part of the clinical psychology doctoral training course, the author completed a research thesis, using Q methodology to determine the factors that were most important to achieving a good quality of life, post stroke and aphasia, from the perspectives of stroke survivors and their spouses. Each stage involved in completing this work presented its own challenges, from gaining ethical and research and development (R&D) approvals, to identifying participants, to gaining consent and completing the Q sort task, through to carrying out the data analysis. The challenges are discussed below.

Gaining Approvals. Due to the potential vulnerability of the participants, resulting from their age and physical and communication difficulties (NHS, 2013) and the nature of recruitment, via NHS employed speech and language therapists (SALTs), thorough university and NHS ethical approvals were required, in addition to R&D authorisation. This was a complex process, with added complications as the research was conducted outside the geographical area in which the author was employed and resided. Furthermore, the SALTs involved in the recruitment process, working in both Nottingham city and county, were employed by NHS and non-NHS organisations, so detailed investigation was required to identify the appropriate R&D services to involve. It was felt that there was a lot of uncertainty around about this process, with each step needing clarification and detailed consideration. Additional obstacles were introduced by the time of year that the approvals were sought; either over the Christmas or Easter breaks, thus contacting the necessary individuals proved difficult on occasions. Altogether, it took about a year to gain ethical and R&D approvals, much longer than originally anticipated. Feelings of frustration were around at times, which were eased by the helpful nature of the people who were involved in supporting the application. Anxiety made an appearance, due to the unknown and ambiguous requirements, and wanting to ensure that all approvals were adequately gained. Personal difficulties in delegating responsibility were acknowledged, with the author wishing to follow up and to check that every step completed by someone else was done thoroughly and in a timely manner.

Recruitment. On gaining the relevant approvals, the process of recruitment was initiated. Speech and language therapists had been consulted throughout the course of designing the study through to recruitment and completion of the Q sort task. The recruitment stage presented a number of obstacles to overcome, and resulted in 11 participants being recruited rather than 20 as originally hoped. Due to time constraints, a period of two months had been allocated to recruitment and data collection, which in reality was not long, in terms of

identifying people to take part, and completing the questionnaires and the Q sort, which itself took much longer than predicted. It was found that the inclusion criteria were quite limiting, and not many clients on the SALT's caseloads met the conditions. In particular, not many aphasic stroke survivors had a spouse, many were widowed, which is perhaps indicative of their stage of life, predominantly being older adults.

Another complication was that of the severity of aphasia accepted by the study criteria. Based on previous research (Hilari, 2011; Hilari and Byng, 2001; Hilari, Byng, Lamping and Smith, 2003) participants were required to score ≥ 7 on the receptive domains of the Frenchay Aphasia Screening Test (FAST; Enderby, Wood, Wade and Langton Hewer, 1987) however, this was only to be assessed by the author, once participants had consented to the study. This method added complications to recruitment, as SALTs were making their best clinical judgments about who would meet this criteria, and therefore avoided referring people who they thought (a) may not meet this cut-off and (b) in their view, who would struggle to complete the Q sort task, to protect the clients and to minimise any potential distress that this recruitment method could generate. This may have resulted in fewer potential participants being introduced to the study, and a slight bias regarding the severity of aphasia of those eventually recruited. An additional complication was the use of the FAST itself, as it is understood that this is used primarily for research rather than clinical purposes. SALTs were therefore not familiar with the clinical presentation of someone achieving the cut off score of ≥ 7 . This may have encouraged a more cautious approach to participant identification, and a bias towards those with milder communication difficulties, to minimise any distress.

Consent. It was paramount to ensure that participants fully understood what participation in the study would entail, and that comprehension abilities were sufficient to be able to complete the Q sort task. When introducing the study, an aphasia friendly information sheet was used (comprising short, simple sentences, emboldened key words and pictures) to aid understanding, and the principles of the Mental Capacity Act (MCA; 2005) were followed so that the author felt

confident that the information had been understood. The FAST, as aforementioned, was used to determine whether or not the stroke survivor would be able to complete the Q sort. Difficulties arose when the spouses' comprehension was in question, rather than that of the stroke survivor, which happened on one occasion. It was not appropriate to carry out the FAST with this spouse, thus the principles of the MCA were essential guidance. The two tests of the MCA were utilised: the spouse met the criteria for the diagnostic test, thus the principles of the functionality test were considered. On assessment, they seemed to have an understanding of the project, were able to weigh up the pros and cons of taking part, to reiterate the information provided when asked, and were able to express their willingness to consent to taking part. On carrying out the Q sort, it became apparent that they needed further support to do the task, which was provided by the author through making some adaptations to the task; breaking down the Q sort into a number of basic steps, and agreeing to complete it over two sessions. On returning to finish the task however, the spouse decided that they did not wish to continue, indicative of their capacity to consent. Although disappointed that the work was not completed, it provided the author with a sense of relief that the capacity assessment was accurate.

Assessing Aphasia. As mentioned previously, there have been some concerns raised through using the FAST and the implications for the sample of participants recruited. It has been debated whether or not the cut off of ≥ 7 on the receptive domains was too high, and therefore unnecessarily excluded some participants who may have had sufficient comprehension to complete the task, with communication aids and support from the author. It was felt that it was somewhat preferable to keep it higher rather than lower, to minimise distress. However, if done again, it might be useful reduce it slightly.

Challenges to the author arose when participants were on the borderline of the cut-off score. One stroke survivor, for example, scored 7 on the appropriate domains, but required some additional help to gain this outcome, which included repetition and clarification of questions.

This was deemed acceptable by the author, as this sort of support was available throughout the Q sort task, and it felt somewhat unethical to exclude this participant when they were willing and keen to take part, particularly because the drive behind the study was to provide this population of people with the opportunity to express their views, as too often they are excluded from such research.

Another comprehension difficulty encountered was presented when one stroke survivor found it hard to understand the study requirements, despite using the aphasia friendly information sheet, and additional support from their spouse and the author, and concluded that they did not wish to take part. The stroke survivor became quite tearful, and the author used her clinical skills to manage this distress and to end their study involvement as soon as possible. It may however, have been appropriate to offer involvement in the study to the spouse without the stroke survivor partaking, as they were keen to participate. However, at the time, this was not deemed the most appropriate course of action, thus neither were recruited.

Lastly, a dilemma that the author has been left reflecting upon is, what the participants actually understood by the Q sort task. The FAST was used as a safeguard to help ensure full comprehension, but was this sufficient? The author has been left wondering whether the participants used the Q sort to indicate what they actually have in their lives at present, rather than what would be important to achieve a good quality of life.

The process of assessing comprehension was a complex one, and raised feelings of uncertainty, and occasionally left the author questioning the decisions made. However, issues were discussed with supervisors and agreed action plans were devised. Actually completing this research with people with aphasia reminded the author how valuable and enjoyable this work is, including the challenges faced, and emphasised the desire to continue working in this field on qualifying as a clinical psychologist.

Clinician Versus Researcher Role. Through completing the Q sort, the participants reflected upon their experiences of the stroke and

communication difficulties, and by doing so, some of the stroke survivors became tearful considering the challenges they currently faced and their feelings. This raised a dilemma for the author, such that the clinical psychologist within her wished to explore the participants' thoughts and feelings further and to provide psychological support, as a need was identified. However, being in the situation as a researcher meant that this was not the capacity of the role to be fulfilled. As a compromise, the author used clinical skills to listen and empathise with the participants, and provided contact details to access appropriate help, in addition to gaining permission to discuss the conversations with their SALT, highlighting concerns, such that the SALTs could investigate the possibility of psychological support. Having this dual role felt quite challenging, and it felt somewhat unnatural not to automatically provide a psychological assessment/ intervention. Nonetheless, by the author's minimal intervention, it was hoped that right support would be implemented, even if it wasn't provided by the author herself.

Data Analysis and Results. Guidance from Watts and Stenner (2012) was used to direct the author through the data analysis stage. It was their clear instruction and reassurance that gave the author confidence to complete an otherwise unknown and daunting task. Feelings of uncertainty and anxiety were elicited at times, primarily because the author had no prior experience of Q methodology, and was keen to produce accurate and meaningful results. Once the number of factors had been decided, it was a somewhat enjoyable and exciting process to determine what they were portraying, and the messages conveyed by the participants. A sense of responsibility and loyalty to the participants was felt, such that it felt important to accurately and honestly interpret and present their opinions and views. One of the key motivations for completing this work was to provide people with post-stroke aphasia a means of voicing their views, which aphasia can often hinder. Additionally, as the factors were supported by two relevant theories, the author felt more confident that they had been interpreted appropriately. It would however, given more time, be beneficial to

complete the Q sort with more participants, to explore the impact of this upon the number and content of the factors. This may clarify which of the two relevant theories identified: (a) the psychosocial stages of development model (Erikson, 1968) or (b) the stages of stroke recovery (Holbrook, 1982; Kirkevold, 2002) was most fitting.

Attending to Feelings

As identified, a number of emotions were present at different stages of completing the thesis. A common theme however, was that of anxiety. Each stage presented different challenges and uncertainty, which then invited anxiety in. The Yerkes-Dodson Law (Yerkes and Dodson, 1908), proposes that a certain level of stress/anxiety can improve performance, but too much can be a hindrance. Throughout the majority of the work, anxiety seemed to drive the author to work hard, to complete each task thoroughly, seek advice from supervisors and those with greater knowledge, and to attend to detail in order to meet their perfectionist standards. According to Belbin's team roles (1981) the author fits the category of 'completer finisher' which is reflected in the way that this piece of work was conducted. Completer-finishers find it difficult to delegate work to others, feeling the need to check the quality of others' work. This was evident throughout the whole process, when the author felt it necessary to liaise closely with relevant others, and to check that work completed by others was done so sufficiently. Frustration was sometimes present, particularly when tasks that were beyond the author's role or ability were not carried out in a timely manner, and the author's work was hindered whilst waiting for other people to complete their contributions. It is acknowledged that this is part of the completer-finisher trait and is useful to be aware of when working with others and to consider helpful means of managing the anxiety or frustration without having a negative impact upon other team members.

It is important to acknowledge that positive feelings were also around during completion of this work, especially when spending time with the participants, carrying out the Q sort, which was really

enjoyable. It seemed to be quite therapeutic for some to think about what made their life good, identifying things that they perhaps hadn't thought of before, and to be able to share the story of their stroke and the experiences they'd had. When the data collection was complete, feelings of accomplishment were present, that the initial project ideas that the author had three years ago, had actually come to fruition and had worked successfully! Excitement ensued in the data analysis stage, when new work and ideas were produced, contributing to the evidence base, which hopefully will act to support aphasic stroke survivors in gaining the rehabilitation that they would like and need.

Re-Evaluating Experience

Throughout the process it felt like finishing this piece of work would almost be impossible to achieve, which brought about anxieties and frustrations, particularly as the author was concurrently completing placements and other assignments, and was not able to solely focus upon the thesis. However, now that it is complete, with interesting and useful results, it feels like a huge achievement, and something to be proud of! The experience of completing NHS research has provided invaluable knowledge and skills that will be of tremendous use for future projects, and has given the author greater confidence in carrying out research in her later career. It is hoped that the expertise and competencies developed can be generalised to other research projects, involving different research methods or populations. It has though, highlighted how much the author values and enjoys working with this group of people, and has confirmed that this is the area in which they see themselves specialising in once qualified.

In terms of personal learning the author has identified the need of having greater confidence in her skills and decision making abilities. All queries and uncertainties were discussed with supervisors and people with relevant expertise, and the author's ideas were generally accepted and agreed with. Furthermore, identifying oneself as a completer finisher, means that perfectionist standards are aimed for and attention

to detail is ingrained in the approach to any task, thus the level of work is likely to be of an acceptable, if not high, standard.

With regards to the research itself, it has been acknowledged that each stage took longer than was predicted, and that it is necessary to allow adequate amounts of time to finish each part of the process. Actual timing of the work was also important, for example, attempting to gain project approvals and asking others to aid recruitment over the Christmas period may not have been the most suitable time to do so! It may be beneficial to change the inclusion criteria, to use a cut-off of ≥ 5 or 6 on the receptive domains of the FAST, and to make greater use of communication aids thus enabling people with a wider range of receptive abilities to take part.

Conclusions

Altogether, although this piece of work has been challenging at times, it has been generally enjoyable, and numerous and invaluable skills and experiences have been developed, which will be of benefit to the author's future career. The most important achievement was that this research demonstrates not only that Q methodology can aid people with aphasia to convey their ideas and opinions, but also that this population of people can certainly be included in research, given that appropriate adaptations are made. The author felt a huge sense of privilege being able to share the personal stories of the aphasic stroke survivors and their spouses at the time of data collection, but now, being able to share such stories with a wider audience through the results of this work. It is hoped that by contributing to the evidence base, this research will inadvertently contribute to the development of more tailored rehabilitation services, leading to more promising outcomes for this population.

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